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Community-Based Interventions for Stroke Provided by Nurses and Community Health Workers: A Review of the Literature

Gayenell S. Magwood, Michelle Nichols, Carolyn Jenkins, Ayaba Logan, Suparna Qanungo, Enia Zigbuo-Wenzler, Charles Ellis, Jr

ABSTRAC1

BACKGROUND: Community-based interventions are vital for facilitating poststroke recovery, increasing community participation, and raising awareness about stroke survivors. To optimize recovery and community reintegration, there is a need to understand research findings on community-based interventions that focus on stroke survivors and their caregivers. Although nurses and community health workers (CHWs) are commonly involved in community-based interventions, less is known about their roles relative to other poststroke rehabilitation professionals (physical therapists, occupational therapists, and speech-language pathologists). Thus, the purpose of this review is to explore research focused on improving community-based stroke recovery for adult stroke survivors, caregivers, or both when delivered by nurses or CHWs. METHODS: A systematic review using Scopus, PubMed, EBSCOhost, MEDLINE, CINAHL Complete, and PsycInfo was completed to identify community-based poststroke intervention studies using nurses or CHWs through August 2018. RESULTS: Eighteen studies meeting inclusion criteria from 9 countries were identified. Details regarding nurses' and CHWs' roles were limited or not discussed. Interventions emphasized stroke survivor self-care and caregiver support and were offered face-to-face and in group sessions in the community and home. A wide range of instruments were used to measure outcomes. The results of the interventions provided were mixed. Improvements were observed in perceptions of health, quality of life, knowledge, self-efficacy, self-management, and caregiver support. **CONCLUSION:** Nurses and CHWs play a pivotal role in community-based care. Evidence suggests community-based interventions facilitate the necessary support for stroke survivors, caregivers, families, and communities to optimize stroke recovery. Data from this review illustrate a continued need for comprehensive programs designed to address the complex needs of stroke survivors and families when they return to their homes and communities.

Keywords: caregivers, community-based interventions, community health services, community health workers, integrative review, nursing, outcomes, stroke

troke is a global health problem with more than 15 million individuals annually experiencing the condition worldwide. Rates of stroke in low- and middle-income countries continue to increase. Stroke-related deaths have declined globally; however, the number of persons having a first stroke,

surviving, and living with the consequences is increasing. ^{1,2} In the United States, approximately 795 000 Americans experience a stroke annually. ³ There is evidence that overall stroke rates have been on the decline in the United States during the last 2 decades. ²

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The most devastating consequence of stroke is long-term disability. Stroke is the leading cause of long-term disability with at least 5 million survivors being left permanently disabled worldwide. 1-3 Many stroke survivors are left with motor and sensory disability that limits their independence and quality of life.³ As a result, some stroke survivors need rehabilitative care to address persisting deficits. Rehabilitative care can occur in multiple settings and from a variety of rehabilitation professionals.4 The predominate approach to stroke rehabilitative care occurs in inpatient, home health, and outpatient settings and emphasizes the goals of the patient, family/caregivers, and friends, in addition to the specialized rehabilitation team (physicians, nurses, physical therapists [PTs], occupational therapists, speech-language pathologists, recreation therapists, psychologists, registered dieticians, and social workers, among others).⁴

Unfortunately, the abrupt and complex nature of stroke and the short length of care in rehabilitative units allow little time for stroke survivors and families to prepare for the challenges of returning home.⁵ Consequently, stroke survivors frequently need assistance and a coordinated stroke recovery plan to facilitate optimal transition to the home setting. In fact, the true impact of disability after stroke is typically not fully realized until the stroke survivor is discharged to their homes.⁶

Approximately 70% of all stroke survivors are discharged to a home setting. Stroke survivors are frequently discharged home to family members who are not prepared or equipped to provide care for stroke survivors with complex care needs. Furthermore, many stroke survivors are discharged from hospitals without any specific posthospital care services in place. Although community or home-based care has the potential for positive impact, there are limitations such as lack of structure in community-based services for poststroke care and regional variation in availability of care and access-to-care issues. Yet, community-based interventions are potentially vital to the stroke survivor's recovery and to offer the needed support for their caregiver(s).

Among the many poststroke rehabilitation professionals are nurses who often serve as coordinators of care and offer direct delivery of a range of interventions in the home and community settings. ¹⁰ To date, less attention has been given to the roles and outcomes of the engagement of nurses in community-based interventions, despite substantial attention being given to home-based stroke care overall. To address this issue, this review was designed to explore the current research related to community-based interventions provided by nurses or community health workers (CHWs) either individually or as part of interprofessional teams. Nurses

and community-based health workers offer separate and overlapping services both designed to create a connection between patients and healthcare systems, facilitate navigation of services to optimize stroke recovery, manage care transitions, limit social isolation, and help determine eligibility of services vital to stroke care. 11,12 Therefore, our review was designed to examine their collective contributions to community-based interventions and to determine the extent that nurses and CHWs have been used in community-based interventions to facilitate positive stroke outcomes and optimal transitions to home and community. For this review, CHWs were defined as a peer navigator, lay health worker, or patient navigator who facilitated delivery of health-related services in the community. Community-based intervention was defined as an intervention, program, or service offered to stroke survivors by nurses or CHWs in the home setting after discharge from an acute care or rehabilitation hospital.

Methods Search Terminology

The research team agreed upon terms, synonyms, and definitions for 4 key areas: CHW or nurse, intervention, stroke, and transition of care. Because interventions were provided to stroke survivors, stroke recovery/ rehabilitation was added to capture CHW or nurse interventions that may be aligned with traditional rehabilitation, although the focus here was not on rehabilitation treatments. After a preliminary search to identify combinations of keywords possible in each prospective database platform, reviewers identified the following combination of terms: [("patient education" OR training OR community OR strategies OR programs) AND ("nurse" or "community health worker" OR "CHW" OR "lay health worker" OR "patient navigator" OR "patient mentor" OR "peer navigator" OR "peer mentor" OR community OR home) AND ("post stroke recovery" OR "post stroke rehabilitation" OR "post stroke" OR "stroke recovery" OR "stroke rehabilitation")]. These terms were used (or minimally adapted) for each database to answer the research questions.

Databases

A systematic search of the terminology was completed using Scopus, PubMed, EBSCOhost, MEDLINE, CINAHL Complete, and PsycInfo. Regardless of database platform, each search was completed using the same process to ensure search techniques specifically complied with the nuances of the database or platform. The search included all studies published through August 2018.

Study Selection

Inclusion criteria included research studies with any intervention that provided community-based care (intervention/programs/services for stroke recovery after discharge from an acute care or rehabilitation hospital) and delivered by nurses or CHWs in home/community settings. Studies with an intervention that focused on stroke survivors after discharge from an acute care or rehabilitation hospital, as well as their caregivers, were also included.

Exclusion criteria for this review included studies that did not involve nurses, CHWs, or a specific stroke-related intervention. Studies involving rehabilitation professionals (PTs, OTs, speech therapists, psychologists, physiologists) were excluded. Published scientific abstracts, protocol studies, ongoing studies, reviews of the literature, editorials, and commentaries were also excluded. Finally, studies not published in English were excluded.

Data Extraction

The search was completed by a medical reference librarian (A.L.), and citations for identified records were uploaded onto a web-based reference management library. Four team members (C.J., M.N., E.Z., and S.Q.) screened titles and abstracts for relevance based on inclusion/exclusion criteria. Any article that was identified as potentially eligible by any member was subject to full text assessment. Next, 3 authors (M.N., C.J., and S.Q.) independently assessed eligibility of each full-text article and extracted the data. A different reviewer independently verified data extraction to check for accuracy. Disagreements were resolved by consensus at each stage of selection, data extraction, and quality assessment.

Search Results

The search strategy yielded 2940 records with 2933 from the computerized search. Hand searches of reference lists of articles selected during the computerized search identified 7 additional articles (see Figure 1 for a summary of selected articles). After removal of duplicates, 2607 records were excluded during title and abstract review. Full texts of 333 potentially relevant articles were reviewed to assess eligibility, of which 315 were excluded because of not meeting inclusion/exclusion criteria. The most common reasons for exclusion were articles that were protocols, reviews, editorials, or commentaries that did not include research results or did not evaluate an intervention, or the intervention was not directly provided by a nurse or CHW. Finally, a list of 18 articles that included community-based interventions delivered by nurses or CHWs was compiled for data extraction, synthesis, and inclusion in this review. All identified articles were accessed for location of study (United States or abroad), who delivered the intervention(s), type of intervention implemented, and summarized

details of the study including study design, population studied, intervention methods, and results.

Results

Overview of Studies

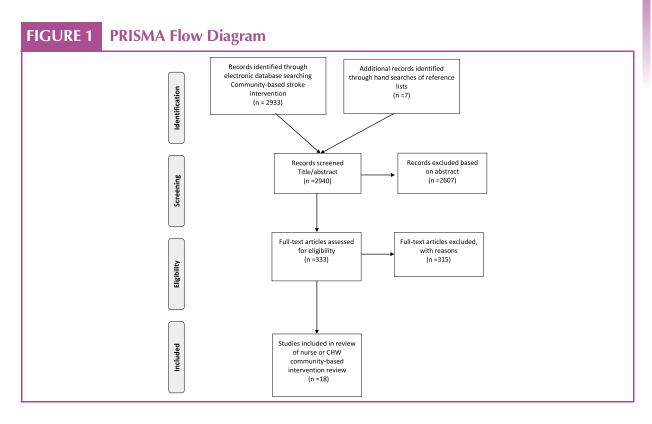
All studies identified and included in this review are summarized in Table 1. Among the 18 published articles in this review, ^{13–30} 7 were completed in the United States,^{24–30} 3 were completed in Canada,^{14–16} 3 were completed in China, ²¹⁻²³ and 1 study each was completed in the United Kingdom, 13 Northern Ireland, ¹⁷ Scotland, ¹⁸ Thailand, ¹⁹ and Nigeria. ²⁰ Study designs included quantitative, qualitative, and mixed methods. Eleven of the 18 published articles were randomized controlled intervention trials. Other designs included a quasi-experimental, nonequivalent control group where randomization occurred at the geographic district level; a randomized pragmatic trial; and 2 prospective studies using preevaluations/ postevaluations. 13,19,26,27 Qualitative designs included mixed-method approaches and programmatic evaluations. 18,21,28,29

Details of Intervention Studies

Sample sizes ranged from 14 to 561 participants; the mean age for stroke survivors ranged from 60 to 75 years, and the age of caregivers ranged from 49 to 64.1 years. Interventions in 3 studies focused specifically on the stroke survivor, whereas 2 focused on the stroke survivor and caregiver. The types of interventions, who delivered the interventions, the length of the intervention, the types of measurements, and outcomes varied substantially across studies. The duration of interventions ranged from 2-3 hours to 12 months; however, most interventions were delivered to the stroke survivor or caregiver and ranged from 4 to 12 weeks. Interventions were delivered by nurses; nurses and "trained call center"; interdisciplinary team that included nurses, peer stroke participants, and nurses; and a "community stroke navigator." The settings where interventions were provided included stroke survivors' homes and community settings such as ambulatory clinics, community health centers, and rehabilitation centers. Those studies that provided services outside the home (eg, ambulatory clinics) completed follow-up evaluations in the home or community setting. All interventions emphasized the provision of resources necessary to promote the physical and/or psychological well-being of the survivors and caregivers.

Intervention Details

Although all researchers disclosed information on the interventions they implemented, the specific details and processes of implementation were frequently



lacking. One-third of the interventions included in this review emphasized "self-management" or the "ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent with living with a chronic disease."31 Other interventions emphasized caregiver management skills or comprehensive skill-building and goal-setting strategies with psychoeducation/information and support components. Interventions were delivered to individuals face-to-face and in group sessions in the community and home. The success of the community-based interventions was mixed across studies; however, the more comprehensive interventions, targeting primarily stroke survivors, were the most effective. Outcomes were measured using over 40 different instruments designed to measure motor recovery, impact of stroke, depression, health status and health-related quality of life.

Intervention Results

Although the specific intervention details were lacking in some studies, many reported positive outcomes. Two studies reported increased stroke-related knowledge/competence, which are critical to the recovery process and risk reduction as part of comprehensive secondary risk prevention. Similarly, 1 study noted that the intervention received resulted in a reduction of at least 1 major stroke factor, and a second study noted increased medication adherence, which ultimately can translate to reduced stroke risk. Other studies reported improvements in poststroke behavioral symptoms among

stroke survivors and caregivers, which included greater optimism, greater satisfaction, improved perceptions of general health, reduced emotional reactions to stroke, and reduced social isolation. 13,23,24,26 Other improvements noted were greater self-enjoyment, selfexpression, coping, connectedness, and overall quality of life. 17,21,28 Å number of studies also reported greater stroke-related self-efficacy and problem solving, which is critical to stroke recovery and stroke risk reduction. 17,22,23 Finally, improvements were noted in poststroke service utilization such as reduced 30-day readmissions and emergency room visits.²⁹ Although postintervention positive results were reported, the lack of details regarding some of the specific interventions should be considered in any interpretation of the overall conclusions being drawn. In addition, the distinction between the role that nurses played in the administration of the interventions (nurse administration of the intervention vs nurse-led interventions) was less clear relative to other healthcare professionals. Furthermore, CHWs' roles were either limiting any specific examination of effectiveness based on clinical background (nurse vs nonnurse).

Discussion

Nurses play a critical role in comprehensive stroke care throughout the stroke experience. In the earliest stages of the stroke diagnosis, nurses play a critical role in the triage of patients with acute stroke onset as well

TABLE 1. Posthospital Community-Based Stroke Intervention Studies Involving Nurses or Community Health Workers

	Community Health W	/orkers	
Author(s), Year	Study Focus	Intervention	General Findings
Burton &	Nursing education of	Stroke nurse follow-up visit	Improved patient perceptions of general
Gibbon, ¹³	stroke survivors/caregivers	within 2 d of discharge and	health, reduced emotional reaction, and
2005		flexible visits thereafter	perceived social isolation at 12 mo
Green et al, ¹⁴	Brief motivational	Nurse-mediated	Greater knowledge change in
2007	interview on knowledge/	motivational counseling	intervention group on self-report
Mayo et al, ¹⁵	behavior	and lifestyle class	questionnaire
2008	Impact of care manager on QOL and healthcare use	Assignment of stroke nurse case manager to monitor	Nursing case management in the first 6 wk
2000	QOL and nearincare use	care via home visits and	did not have an impact on HRQOL or
		telephone	healthcare use.
Mayo et al, ¹⁶	Impact of method of	Assignment of stroke	No significant differences between 2
2009	evaluation on response	nurse case manager assist	groups
	shift	transition to home	
McKenna	Stroke self-management	Bridges Stroke	Greater change in self-efficacy and QOL
et al, ¹⁷ 2015	program	Self-Management	over a 6-wk period and stroke survivors
40		Program	showed less decline in QOL at 3 mo
Kidd et al, ¹⁸	Stroke self-management	Nurse-led tailored	Intervention perceived feasible and
2015	intervention	stroke self-management	acceptable to stroke survivors and stroke
		program	nurses
Pitthayapong	Poststroke care program	4-wk program to enhance	Improved knowledge and skills among
et al, ¹⁹ 2017		motivation/skills	caregivers after intervention
Wahab et al, ²⁰	Feasibility of short-term	of caregivers Nurse-led group outpatient	No significant differences in clinic BP at
2017	nurse-led education on BP	clinics focused on	a 2-wk visit
2017	nuisc-ica caacation on bi	education and skill-building	a Z-vvk visit
Sit et al, ²¹	Creative arts activity to	Nurse-facilitated Leisure	Enhanced self-enjoyment, self-expression,
2017	promote wellness	Art-based Creative	and connectedness with others; provided a
	•	Engagement	nonverbal mechanism for expression of
			thoughts
Lo et al, ²²	Self-efficacy program on	Nurse-led self-efficacy/	Improvements in stroke self-efficacy,
2018	stroke recovery	self-management program	self-management outcome expectations,
			and behavioral performance at 8 wk
Cheng et al, ²³	Evaluate effectiveness of	Caregiver educational program	Improvements in competence, problem
2018	program for caregivers	for caregiver competence,	solving, satisfaction in social support,
		problem solving, and burden	and family functioning
Studios complet	ed in the United States	symptoms	
Bakas et al, ²⁴	Program for caregiver	Nurse-delivered intervention	Improved optimism, task difficulty, and
2009	needs and skill building	by mail and phone address;	threat appraisal at 4 wk
2003		caregiver needs/concerns	anear appraisar at 1 m
Flemming	Risk factor prevention	Nurse-delivered prevention	61% of intervention participants
et al, ²⁵	program	program of individualized	reached reduction goal of ≥ 1 major risk
2013		education, motivational	factors
		interviewing, and risk-factor	
. 26		modification goal setting	
Bretz et al, ²⁶	Patient transition program	Steps Against Recurrent Stroke	Increased medication adherence, strong
2014	to facilitate recovery	program to promote QOL after	patient satisfaction, and significant
		stroke with a focus on	differences in health-related outcomes
		medication management, well-being, and identification	
		of educational needs	
Bakas et al, ²⁷	Caregiver education	Nurse-led Telephone	Caregivers had a reduction in depressive
2015	program	Assessment and Skill-Building	symptoms and greater improvement in
	. 0	Kit (TASK II) for caregivers to	life changes.
		build skills for needs assessment	<u> </u>
			(continues)

Author(s), Year	Study Focus	Intervention	General Findings
Robinson-Smith et al, ²⁸ 2016	Program for couples to improve coping	Nurse psychoeducational education program focused on strengths and challenges couples face.	Improved coping and quality of life in conjunction with decreased depressive symptoms
Kitzman et al, ²⁹ 2017	Care coordination for community transitions	Home or telephone or office visit to assist with community resources, discharge plans, and compliance with rehabilitation plans	Minimal number of 30-d hospital readmissions and ED visits; compliance with medications (92%), physician visit (96%), and outpatient rehabilitation visits (70%)
Kirkness et al, ³⁰ 2017	Behavioral intervention to reduce depressions	Nurse practitioner led 6-session in-person or telephone intervention to address strategies to deal with depression	No significant reduction in depression over usual care

as initial assessment and timely transition within the healthcare system offering stroke care.³² Similarly, after discharge to the home, nurses and CHWs offer critical support to stroke survivors and their families necessary to transition back to their communities. 11 Less attention has been given to the roles of nurses and CHWs offering community-based care for stroke survivors with persisting disabilities with a greater focus being on rehabilitation services (PTs, OTs, speech-language pathologists, recreation therapists, etc). Whereas rehabilitation professionals are critical for improving sensory and motor impairments, nursing and CHW-led interventions are equally critical to limiting the likelihood of recurrent stroke and assisting the stroke survivor in reducing risk of comorbid conditions (hypertension, high cholesterol, diabetes, etc). In many aspects, nurses are not only involved in early stroke management but are more likely to have the longest-term involvement with stroke survivors in the home and community settings along with CHWs.

Nurse- and CHW-led interventions identified in this study highlight the impact of those interventions in reducing healthcare utilization, improving knowledge of stroke risk and comorbid conditions, reducing risk, improving self-efficacy, and improving quality of life. Nurse and CHW interventions are also critical to improving caregiver knowledge and their ability to assist stroke survivors. The most effective interventions seem to be those that are comprehensive in nature and offer specific strategies for addressing stroke-related risk factors. In addition, such interventions are important for offering the stroke survivor and caregiver critical information or educational materials to improve their understanding of the complex nature of stroke.

Understanding the larger impact of nurse- and CHWled interventions is, in many aspects, limited by a wide range of study designs and outcome measures used in published literature. In this review, the predominate study design was the randomized controlled trial; however, interpreting the studies collectively was limited by the high number of different outcomes and measurement instruments used across studies. Intervention outcomes emphasized change in knowledge as well as clinical measures of stroke risk and stroke risk factors. Consequently, the study results collectively were mixed, with several studies reporting statistically significant improvements in groups receiving interventions compared with controls; however, other studies showed no difference in outcomes despite the interventions.

To determine the true effectiveness of nurse- and CHW-led interventions, systematic and programmatic research is required with a focus on specific outcome types (education, clinical, etc). In the absence of such organized research, stroke healthcare providers are left with many unanswered questions regarding the effectiveness of such interventions or which interventions are most likely to improve stroke outcomes. This review suggests that there is a critical need for researchers, clinicians, stroke survivors, and their caregivers to identify priorities for community-based research that offers the best information to enhance the transition from organized stroke care in healthcare systems to home and community. In consideration of change in stroke demographics, a greater focus should be on diverse (underresourced populations), high-risk, and younger stroke populations. Similarly, there seems to be a need for more feasibility and pilot trials to determine which interventions are most successful in the home/community setting and facilitate optimal stroke outcomes.

This review has limitations. First, this review was limited to articles published in English. Second, because of the wide range of research designs and outcome measures used across studies, it was difficult to

adequately compare interventions. Third, several studies, although community based, lacked mention of nurses or CHWs and therefore were not included. Fourth, the sample sizes of stroke survivors and caregivers varied significantly across studies, making it difficult to determine the likelihood of generalization of studies to other stroke populations. Fifth, although stroke is a global epidemic, only a few countries are represented in the studies identified.

Despite these limitations, the need for further research related to contributions of nurses and CHWs is urgently needed. Regardless of world geographical region, stroke is a medical and societal disorder with undesired physical and mental consequences for stroke survivors and their families. A better understanding of interventions that will improve the transition from hospital to home and community for stroke survivors can be used to improve stroke outcomes globally.

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