# Creation of a Support Group for Ruptured Brain Aneurysm, Arteriovenous Malformation, and Hemorrhagic Stroke

Joshua L. McDaniel

College of Nursing, East Carolina University

Doctor of Nursing Practice

Dr. Dianne Marshburn

April 23, 2021

#### Abstract

Hemorrhagic strokes, which also consist of ruptured brain aneurysms and arteriovenous malformations, carry a higher risk of physical and cognitive disabilities than ischemic strokes. Survivors will most likely suffer challenges that include social isolation, depression, medical complications, and secondary stroke prevention. Navigating life after an event can be burdensome for the survivor, family, and caregivers by placing new responsibilities and strains within the relationship. Enhancing social networking and support through community-based support groups can be an effective way to improve recovery and the health and well-being of survivors and caregivers. Before implementing this project, there were no support groups available for this population within central North Carolina. Limited financial and human resources within the community have made improving community outreach to this population difficult. To address the community's lack of support, a support group was created to empower survivors and their caregivers by providing an outlet to obtain appropriate support, education, and socialization. Through gaining necessary support and socialization, better outcomes will be achieved, and the community could see an improvement in patient satisfaction, decreased readmission rates, and fewer reoccurrences. Through evaluating the program, it was found that having an engaged multidisciplinary planning team as well as organizational and leadership buyin and support were essential to success. A broad and varied recruitment strategy should be used and implemented as early as possible. Social media can help build relationships and promote socialization among participants in an online environment.

*Keywords:* support group, ruptured brain aneurysm, arteriovenous malformation, hemorrhagic stroke, social networking

# Creation of a Support Group for Ruptured Brain Aneurysm, Arteriovenous Malformation, and Hemorrhagic Stroke

Abstract	2
Section I: Introduction	5
Background	5
Organizational Needs Statement	6
Problem Statement	9
Purpose Statement	9
Section II: Evidence.	10
Literature Review	10
Evidence-Based Practice Framework	
Ethical Consideration and Protection of Human Subjects	
Section III: Project Design.	22
Project Site and Population	
Program Planning Team	24
Project Goals and Outcomes Measures	25
Implementation Plan	27
Timeline	31
Section IV: Results and Findings	33
Results	33
Outcome Data	34
Discussion of Major Findings	35

Section V: Interpretation and Implications
Cost-Benefit Analysis44
Resource Management
Implications of the Findings
Sustainability
Dissemination Plan
Section VI: Conclusion
Limitations55
Recommendations for Others
Recommendations for Further Study
References
Appendices69
Appendix A: Literature Matrix69
Appendix B: Support Group Session Evaluation Tool
Appendix C: Program Planning Team Evaluation Tool
Appendix D: Support Group Session Guidelines
Appendix E: Session Agenda
Appendix F: Support Group Flyer
Appendix G: Project Implementation Timeline
Appendix H: Project Budget
Appendix I: Support Group Announcement Letter
Appendix J: Doctor of Nursing Practice Essentials

#### **Section I. Introduction**

## **Background**

Overall, stroke is the leading cause of adult disability in the United States (US) and affects about 795,000 people annually (Centers for Disease Control and Prevention [CDC], 2020). When comparing the two main types of stroke, ischemic and hemorrhagic, one carries a significantly higher risk of disability and mortality than the other. Hemorrhagic strokes, which consist of either a ruptured brain aneurysm (RBA) or arteriovenous malformation (AVM), account for 15% of all strokes but are responsible for 30% of stroke deaths (Joe Niekro Foundation [JNF], 2020a). Of all the hemorrhagic strokes, 50% of people will die before they ever reach the hospital, 25% will suffer a delayed death, and the remaining 25% will most likely suffer severe physical and cognitive disabilities that can significantly impact their way of life (JNF, 2020b).

Navigating life after an RBA, AVM, or hemorrhagic stroke can not only be burdensome for the survivor but also the family and caregivers as well. Many survivors face challenges that include social isolation, depression, medical complications, secondary stroke prevention, cognitive changes, and physical disabilities (American Stroke Association [ASA], 2020). These new challenges, coupled with inadequate support, can disrupt family roles by placing new responsibilities and strains within the relationship and potentially lead to a poor post-stroke outcome (Amatangelo et al., 2017).

Overwhelming evidence from multiple studies has shown that enhancing stroke survivor's and caregiver's social networking and support can improve recovery and the health and well-being of both stroke survivors and caregivers (Amatangelo et al., 2017; ASA, 2017). Multiple organizations have shown that community-based support groups effectively avoid

social isolation and provide proper support to survivors and their caregivers (ASA, 2020; Brain Aneurysm Foundation, 2019; JNF, 2020b; National Institute of Neurological Disorders and Stroke [NINDS], 2019). Providing support for patients and their caregivers after a stroke is essential in the rehabilitation process and must be a priority within the healthcare system.

# **Organizational Needs Statement**

Poor psychosocial support among stroke survivors has been linked to poor outcomes after stroke (ASA, 2020). The role caregivers and families play in the survivor's support is vital to positive results (JNF, 2020b). Overwhelming evidence from multiple studies has shown that enhancing stroke survivor and caregiver social networking and support can improve the wellbeing and health of the survivor and their caregivers, but also lead to faster and more functional recovery (Amatangelo et al., 2017; ASA, 2017; JNF, 2020b; NINDS, 2019). In contrast, stroke survivors with a smaller social network and less support were found to have more difficulties adjusting to their disabilities and had a higher rate of recurring stroke (Amatangelo et al., 2017).

Providing support for patients and their caregivers after a stroke is essential in the rehabilitation process and helps them return to as healthy a life as possible. Multiple organizations have shown that community-based support groups are an effective way for survivors and their caregivers to get the support they need while minimizing social isolation (ASA, 2020; JNF, 2020b; NINDS, 2019). Support groups empower survivors with knowledge and emotional support by providing a positive environment that allows them to share their thoughts and experiences with others in similar situations (ASA, 2020). By participating in a support group, survivors and their caregivers can promote good health and good quality of life by having an avenue that allows for the development of new friendships, social networks, coping strategies, and a way to obtain information from healthcare professionals (JNF, 2020b).

Amatangelo et al. (2017) reports that even though overwhelming evidence shows that providing support in the post-stroke phase improves outcomes, this population's emotional and support needs are not adequately met by community-based health centers. The community's lack of support points to an overwhelming need to make a change in practice that will assist survivors and their caregivers in acclimating to their new way of life. Community-based support groups are an excellent way to bridge this gap in support and provide a vulnerable population with the resources to build and maintain social networks and enhance the quality of life.

Currently, there are no support groups available within central North Carolina (NC) to provide the much-needed resources to this population. The lack of support groups places the survivors and caregivers at higher risk for adverse outcomes and highlights the community's opportunity to provide the best evidence-based care. Therefore, a support group for RBA, AVM, and hemorrhagic stroke patients will be created and implemented in central NC to address this gap in care.

The project partner is a Joint Commission Certified Comprehensive stroke center located within central NC. The center is a medium-sized not-for-profit hospital established to serve its local community and neighboring counties by providing a full range of healthcare services and promoting community wellness. They work closely with other care facilities, emergency medical service organizations, and community organizations. In collaboration with the stroke center, a local neurosurgery practice will help create and execute the support group. The stroke center will fulfill its mission of improving its community's health and wellness by developing and implementing a support group for RBA, AVM, and hemorrhagic stroke survivors and their caregivers. Further, the community, survivors, and their caregivers will receive a much-needed

resource that will help reduce the overall burden of stroke within the community and provide a venue that will improve the quality of life.

Limited financial and human resources within the community have made improving community outreach to this population difficult. The stroke center admitted 171 hemorrhagic stroke patients into its acute care center in 2019 (Cone Health, 2020a). It has the responsibility to ensure its patients have the resources they need to function at their highest level possible. With this support group's creation, the stroke center's mission to improve their community's health will be achieved, survivors and caregivers will have available support, and the community has the potential to decrease its overall burden of stroke.

Healthy People 2020 (HP2020) and Healthy North Carolina 2020 (HNC2020) includes in their objectives to decrease stroke deaths (NC Department of Health and Human Services [NCDHHS], 2019; US Department of Health and Human Services [USDHHS], 2020). HP2020 further includes in its objectives to increase the publics' knowledge of symptoms and how to respond to a stroke (USDHHS, 2020). The World Health Organization (2016) states that a global response to stroke is needed and is in development with its partners to create new stroke rehabilitation management guidelines. With such a high rate of mortality and disability, educating the public on stroke through support groups is essential to increase awareness and achieve the goals of HP2020 and HNC2020.

The creation and implementation of a support group within central NC align with the Institute for Healthcare Improvement's (IHI) Triple Aim framework to improve the health of a population (Institute for Healthcare Improvement, 2020). This support group aims to improve care delivery and empower the survivors and their caregivers by providing an outlet to obtain appropriate support, education, and socialization. Through gaining necessary support and

socialization, better outcomes will be achieved, and the overall knowledge base related to stroke within the community will rise. With a rise in knowledge and a decline in complications, a decrease in stroke's overall burden and financial impact will likely occur.

#### **Problem Statement**

After someone suffers from an RBA, AVM, or hemorrhagic stroke, they face varying degrees of cognitive and physical impairment and must adjust to their new normal. Support groups play a pivotal role for survivors and caregivers as they navigate the challenges they face and help them live more meaningful lives. Not having a support group available puts the survivor and their caregivers at risk for adverse outcomes and prevents the stroke center from improving the health of this population within the community.

## **Purpose Statement**

The purpose of this project is to create, implement, and sustain a support group in central NC for RBA, AVM, and hemorrhagic stroke patients and their caregivers. With the creation of a support group, the stroke center can fulfill its mission to improve health throughout its community.

#### Section II. Evidence

#### **Literature Review**

A literature review was performed to assess the current recommendations and information available relating to support groups and stroke. Databases were explored via the university library website and included the Cumulative Index to Nursing & Allied Health Literature (CINAHL) database, PubMed, and Google. The MeSH terms used were Support Groups, Systems Implementation, Program Implementation, Program Development, Community Networks, Communities, Stroke, Stroke Patient, Implementation Science, Quality Improvement, Practice Patterns, Decision Support Systems, Management, and Personnel Management. After searching the databases with the MeSH terms resulted in a total of 940 articles.

The results of the literature search were narrowed by adding inclusion and exclusion criteria into each database. For further review, articles must have been written from 2015-2020, from primary and secondary literature sources, written in the English language, peer-reviewed, and evidence-based. To further refine the results and ensure the information's validity, Melnyk levels of evidence were applied. Articles meeting level I to level IV were retained for further review (Melnyk, 2016).

Applying the inclusion and exclusion criteria resulted in discarding 692 articles and retaining 248 articles for further review. Of those 248 articles, the abstracts were read for crucial concepts relating to stroke and support group creation, implementation, and sustainability. Articles that were irrelevant or redundant were omitted. After gleaning the abstracts, 55 articles were chosen for further review. The 55 articles were read in their entirety, and articles that added value to the project were kept. After the literature search, 14 articles that met the inclusion criteria were deemed pertinent to this project and retained (Appendix A).

## Current State of Knowledge

The literature search did not provide any guidelines for the implementation of stroke support groups. However, multiple organizations and studies have confirmed that support groups are beneficial and are ways to improve patient outcomes (Childers & Rutherford, 2017; Evans et al., 2020; Lund et al., 2018; McGuire et al., 2015). A broader search of the literature provided recommendations for who and how to start a support group.

The literature provided overwhelming evidence relating to the benefits of using support groups among various populations. Benefits that are well documented include decreased readmissions, decreased reoccurrence rates, and increased feelings of hope and empowerment (Watson et al., 2016). While much of the literature focused on the patient, a few articles presented evidence that indicated supporting both the patient and caregiver provided the most benefits (Childers & Rutherford, 2017; Evans et al., 2020; Malini, 2015; Warshaw et al., 2019; White & Schweickert, 2015).

McGuire et al. (2015) discussed creating a support group for multiple sclerosis patients using a group therapy model. The group therapy model uses a psychoeducational approach and focuses on peer support aspects, reducing alienation, and fostering an atmosphere to express emotions. Meetings should be structured to include an educational component that presents evidence-based interventions, a therapeutic component, and an interactive component to ensure implementation of the disseminated information (Evans et al., 2020; McGuire et al., 2015).

Both Childers and Rutherford (2017) and Pinxsterhuis et al. (2015) suggest using a client-centered approach when developing a support group. The client-centered approach places emphasis on a respectful, collaborative relationship between healthcare providers and the patient. This type of relationship equalizes the power within the patient-provider link and is said to foster

a more positive relationship that facilitates choice and sets goals based on those choices. Using a client-centered approach has been shown to improve healthcare services and providers' satisfaction levels and improve symptoms and functional outcomes.

Sullivan et al. (2018) addressed common challenges that affected support group implementation and provided strategies to prevent these challenges. Challenges such as human resources, team dynamics, infrastructure, resources, location, attendance, and leadership support were noted as barriers to successful implementation. Support groups were able to overcome these barriers by improving communication between team members, utilization of technology, creative use of team members, and obtaining additional resources. After reviewing all the recommended strategies, organizational function processes, infrastructure, and program fit were noted as critical areas to address to aid in preventing many barriers from occurring (Sullivan et al., 2018).

Lund et al. (2018) reported using support groups to re-orient people to their new life poststroke and exchange information with peers. Key topics discussed during the meetings focused
on secondary stroke prevention, avoiding falls, social networking, medication, nutrition, and
cognitive exercises (American Stroke Association [ASA], n.d.; Lund et al., 2018). Multiple
methods were used to deliver the content and consisted of peer discussion, educational lectures,
self-reflection, and occupational therapy. The interventions were conducted during the meetings
as a group, and the participants were asked to reflect on the importance of the intervention and
how it impacted them in their daily lives (Lund et al., 2018).

In the initial stages of creating a new support group, a community partner should be identified, and a program planning team created (Roush et al., 2015). A community partner can consist of any citizen, health care worker, community leader, cultural group, or individual affected by a particular condition. Finding additional community partners is an essential aspect

of the creation, implementation, and longevity of a support group. National, state, or county organizations might have resources available to provide ideas about structuring the group, stroke resources, support services, and contacts to help build the group (Childers & Rutherford, 2017). Other local support groups can be valuable resources to assist in the planning and implementation phases (ASA, n.d.).

When developing a meeting plan, Childers and Rutherford (2017) warn to avoid restrictive schedules that do not allow a free flow of open communication. Allowing for a flexible meeting style allows the participants to choose the meeting's flow and strengthen the rapport between them and organizers. It was shown that maintaining open communication lines with participants helped the participants take ownership of the group and helped maintain organizational accountability. Being alert to the group's desires and executing what the group wants will further help establish trust and increase member satisfaction.

To further increase the participants' involvement within the group and ensure the meeting consists of relevant topics, it was recommended to have potential members fill out a questionnaire before the first meeting or periodically during the year (Chesman et al., 2017; Childers & Rutherford, 2017). Survey questions included potential topics and speakers, meeting location, meeting structure, confidentiality, and general suggestions and comments. Childers and Rutherford (2017) reported that their member questionnaire results revealed that survivors and their caregivers desired time individually to discuss topics specific to them. Knowing this preference can help acquire an adequate meeting facility that can handle this type of arrangement.

Program attendance and retention were common themes in the literature. Multiple articles provided recommendations on improving program attendance and retention (ASA, n.d.; ASA,

2020; Chesman et al., 2017; Sullivan et al., 2018; Watson et al., 2016). Common sources for members included provider referrals, public health agencies, healthcare professionals, and social services (ASA, n.d.). Other ways to reach potential members consisted of recruitment flyers, Facebook pages, text messages, and emails (Chesman et al., 2017; Gabbe et al., 2017).

To help establish consistency and predictability within the sessions, Zavoda (2015) recommends developing rituals and traditions. Rituals and traditions, such as serving coffee, snacks, and essay reading at the beginning of the sessions, are easy ways to set expectations. The American Stroke Association (ASA) (n.d.) states that naming the support group can improve group cohesiveness and build a sense of identity. Infusing consistency and structure into each session can help the participants form stronger bonds with each other and ultimately increase the group's sustainability.

Costs associated with running a support group were discussed in multiple articles and focused primarily on costs related to participation or the costs incurred by the hosting organization. According to the literature, most existing support groups function free of charge to the participants (Brooker et al., 2017; Gabbe et al., 2017; Im et al., 2016). Some support groups accepted donations to help fund refreshments and activities and were done anonymously to avoid members feeling obligated to donate. One article discussed organizational costs related to support groups with staff salaries, supplies, food, and transportation as the most frequently reported costs. Many of these costs were covered by government agencies, grants, and donations.

#### Current Approaches to Solving Population Problem

The literature supports the creation of a support group as an effective intervention for stroke patients and their caregivers and can promote socialization and improved quality of life.

Identifying current community resources can be a significant endeavor as it may provide insight

and collaboration from existing resources (Childers & Rutherford, 2017). Once the decision to create a support group has been made, community partners and a sponsoring agency will need to be identified to begin the process of program creation (Childers & Rutherford, 2017; Roush et al., 2015).

### Evidence to Support the Intervention

The purpose of this project was to create a support group based on the most current evidence that will address the lack of a program for RBA, AVM, and hemorrhagic stroke patients and their caregivers in central NC. A client-centered approach that Childers and Rutherford (2017) and Pinxsterhuis et al. (2015) recommended was used. Using this approach as an effective tool for creating a successful support group will ensure an open and collaborative relationship between the participants and organizers. Multiple organizations were contacted to help fund program costs such as transportation and refreshments and decrease the likelihood of financial barriers hindering participation.

Corporate sponsors that have an interest and benefit from seeing the support group succeed were sought to help support the project and increase sustainability. In addition to corporate support, a key group of community partners will be established to organize and facilitate the meeting (Childers & Rutherford, 2017). Multiple methods of acquiring members will be used, including community publicity and provider referrals. A survey directed at program participants will be used to help identify the preferences and potential topics that will be discussed during the meetings (ASA, n.d.; Chesman et al., 2017; Gabbe et al., 2017).

#### **Evidence-Based Practice Framework**

The RE-AIM framework was chosen to ensure the intervention's efficacy and help guide the project through creation, implementation, and sustainability. RE-AIM is an acronym that represents five dimensions that together determine the impact on public health. The dimensions consist of Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM, 2020). The RE-AIM framework was created to report results from research consistently. It was later used to organize existing literature reviews on disease management and health promotion (Aziz et al., 2018). More recently, it has been used to aid in program planning and improve the chance the intervention will succeed during implementation.

The RE-AIM framework will be used to assist in developing a support group that focuses on using current evidence-based interventions. Based on the framework's dimensions, a systematic approach to integrating new approaches to practice will be incorporated and will address the challenges that face the implementation of a support group. The RE-AIM framework would be utilized as follows:

R: informing potential participants that a new stroke support group for them exists within their community

E: evaluating admission and readmission rates, assessing program effectiveness among participants through surveys, and making updates as needed

A: ensuring adequate support for successful meeting and sustainability along with buy-in from local organizations

I: using an evidence-based approach that follows the recommendations from the literature as well as expert input and participant feedback

M: implementing appropriate organizational and team member support, the support group will benefit from continually evaluating program outcomes and ensure program goals are being met

Although evidence to support the benefits of support groups for stroke patients is well established, implementing the program successfully, evaluating the process, and creating sustainability will benefit from using the RE-AIM framework. The framework will further provide direction as to potential strengths and weaknesses of the intervention, but will also help inform about the impact on public health, decision-making process, and translation of the research into practice (Jaipakdee et al., 2015).

In addition to the RE-AIM framework, the program planning team will perform monthly Plan, Do, Study, Act (PDSA) cycles focusing on process evaluation and improvement. PDSA cycles are a four-step framework that consists of four phases: planning, doing, studying, and acting. Using PDSA cycles offers an efficient way to implement a change and track its effectiveness (Institute for Healthcare Improvement, 2021). The PDSA method was chosen as a program evaluation tool due to its ability to offer ongoing improvement opportunities and work well with the monthly cycle of planning team meetings and support group sessions. Using PDSA cycles will allow the program planning team to take a systematic approach to implement and evaluate changes from one planning team meeting to the next.

During each planning team meeting, input from the program planning team, evaluation tools, and past PDSA cycles will be critically analyzed. After analyzing the information, the plan stage will begin with the planning team deciding on changes to the process that need to be made. The do stage will begin at the planning team meeting's conclusion and be executed throughout the next month. The study stage will start during the following program planning team meeting

and be assessed for its effectiveness. The act stage consists of the program planning team accepting the new plan or rejecting it. If the plan was rejected, ways to improve the plan would be developed, and a new PDSA cycle will begin.

# **Ethical Consideration & Protection of Human Subjects**

One of the essential elements of an effective support group is providing a safe and ethical environment for its members to come together and share their thoughts openly. The 2014 American Counseling Association (ACA) Code of Ethics states that the program facilitator's primary responsibility is to ensure that each member's dignity is respected and their welfare is promoted (American Counseling Association, 2014). To provide the most therapeutic environment, many ethical issues need to be considered by the program committee.

Concerning any program implementation project that involves humans, the principles of beneficence and non-maleficence are cornerstones in the creation, implementation, and continuance of the program. The benefits of support groups far outweigh the risks involved with a lack of social support and are backed up by the literature. Direct physical harm due to participation in this support group is highly unlikely. However, psychological harm due to anxiety, invasion of privacy, and stress is a possibility. Addressing the many ethical considerations will help to diminish this risk and provide the best outcomes for the members. These two main guiding principles are embedded within this project by addressing ethical concerns such as confidentiality, anonymity, privacy, dignity, trust, transparency, accountability, and equity.

In many one-to-one support settings, confidentiality and ethical considerations are easily discussed with the participant, and questions answered. In other support settings with multiple members, explaining ethical issues and addressing individual concerns can be difficult due to

trust and privacy issues. Ensuring that each member understands the importance of confidentiality and the ethics involved in participating in a support group is critical in developing a therapeutic environment.

Each meeting will consist of members and facilitators with varying degrees of knowledge concerning ethical and confidentiality considerations. Group rules will be established by the program planning committee and discussed along with policies and ethical considerations at the beginning of each meeting. Members will have the opportunity to ask questions within the group or in private and be aware of the organizations sponsoring the support group and any conflicts of interest. Having each group member agree not to disclose any of the information discussed during the sessions will promote confidentiality, privacy, and anonymity and could aid in establishing more trusting relationships. Further education will be provided on the exceptions to confidentiality as required by law.

To help respect each member's privacy, no one is required to discuss or participate in anything they do not wish to and has the right to refuse at any time. Each member's dignity will be respected by ensuring that no member is subjected to being humiliated or abused in any way. Attendance will be on a voluntary participation basis. Each member has the right to withdraw from sessions whenever they desire and will not be subjected to coercion or pressure. Members that choose to remove themselves from a session will not be asked for an explanation or penalized for their decision by the program committee. It will have no impact on their participation in future sessions.

Informed consent will be obtained from each member prior to beginning the questionnaire designed to evaluate the program process and outcomes. Each participant will be fully informed about what data will be collected and how it will be used. The facilitators will

only assess and collect relevant data pertaining to the program to evaluate the process for improvement. No identifying information will be requested or recorded in the data collection and evaluation process to maintain anonymity. The identity of the participant will remain completely anonymous.

The support group is equal to everyone and open to anyone who wishes to participate.

Advertising material is disseminated among the many healthcare facilities that this population seeks care. The meeting site is located centrally within the community and is easily accessible to public transportation. The site was also well equipped to accommodate members with disabilities or other limitations.

### Formal Approval Process

To gain official approval for this project, reviews from the Institutional Review Board (IRB) of the university and health system were attained. The project initially went through the university IRB process. The project lead completed the university IRB verification process using the IRB Quality Improvement (QI)/Program Evaluation Self-Certification Tool. After obtaining approval from the faculty lead, the tool was submitted online. Subsequently, the university deemed the project as quality improvement (QI) and program evaluation and not requiring any further IRB review.

The health system's research council was then contacted for direction as they are the governing committee over IRB approval. To gain institutional approval, the project required a preliminary IRB review before being submitted to the Nursing Research Council (NRC) and the IRB for approval. The process began with reviewing the health system's flowchart for nursing research projects and the step-by-step checklist of the required steps to gain institutional approval. Completion of the Social-Behavioral-Education Researchers and Biomedical

Responsible Conduct of Research Collaborative Institutional Training Initiative (CITI) modules was required and completed by the project lead. The certificates of completion were retained and provided with the health system's IRB documents.

One of the initial steps was to choose a project navigator (PN) from within the health system to help guide the review process. The project lead selected the PN based on their research experience and as a clinical nurse specialist in neurosciences. A meeting was scheduled with the health system's IRB committee chair, the PN, and the project lead to discuss the project, review process, and required documents. An IRBnet.org account was created to upload completed documents for health system review and track the approval process. The project was officially submitted for institutional review on July 15. After evaluating the project, the health systems NRC approved the project on July 21. The IRB determined the project did not constitute research and therefore did not require a formal review, and permission to move forward with the project was granted on July 27.

## **Section III. Project Design**

## **Project Site and Population**

Selecting the right location and reaching the target population was essential in planning for program implementation, as it is linked with attendance and sustainability. The program planning team decided on the support group's location after examining the literature recommendations and assessing the available resources. After discussing site location, the committee selected a meeting room within the local community hospital due to its abundance of resources, ease of scheduling, and accessibility to participants.

## Description of the Setting

The support group meeting location is within the community's largest and most comprehensive medical center in a five-county region. The medical center is a 517-bed teaching facility that includes a referral center and a women's and children's center (Cone Health, 2020b). The facility provides a full array of stroke care and is a Joint Commission Certified Comprehensive Stroke Center. Created in 1953 through a trust to memorialize a local community member, the health center has a long history of serving the community by delivering exceptional and compassionate healthcare.

The selected meeting site offers a central location within the community and provides participants a degree of anonymity from the general public when attending meetings. The site has easy access to regional and city public transportation, is close to many major thoroughfares, has ample covered parking, complimentary valet service, and access to wheelchairs and safety escorts. Participants can opt to use the center's complimentary valet service or park in the easily accessible parking deck. From the parking deck, a covered walkway leads to the main entrance. Once inside the main entrance, participants can choose to take the elevator or stairs located in the

main entrance lobby down one floor. After exiting the elevator or stairs, there is a small common area with restrooms and four meeting rooms of varying sizes. The support group meeting location is the largest of these rooms with a capacity of 50 people and includes audio and video equipment and an area for refreshments. The room is fully equipped with tables and chairs that can easily be moved into different configurations.

The cost associated with acquiring a meeting space was another factor that played into the decision. Due to the health system's commitment to community involvement, it donated the room to the group and scheduled two years' worth of meetings. Being able to schedule sessions long-term allows for increased group stability and sustainability. Along with using this space free of charge, the group can take advantage of the many other resources the health center offers.

## Description of the Population

The support group is open to everyone within the community with no restrictions and operates voluntarily. This quality improvement project's target population includes ruptured brain aneurysm (RBA), arteriovenous malformation (AVM), and hemorrhagic stroke patients and their caregivers who have recently been seen within the comprehensive stroke center or neurosurgery office. Participants coming from the comprehensive stroke center will typically have been recently discharged from the hospital after suffering an acute event. These participants usually receive post-discharge care at the neurosurgery office, where further recruitment attempts can be made. For patients that have sustained an RBA, AVM, or hemorrhagic stroke in the past and continue to receive follow-up care at the neurosurgery office, support group information will be provided at each visit. In addition to recruiting the survivors, caregivers and support people present with the survivors during their visits will be educated and encouraged to participate in

the sessions. Participants ages are typically over the age of 30; however, AVMs and RBA can affect individuals much younger.

Due to the many impacts RBA, AVM, and hemorrhagic strokes can have on an individual, many survivors have been cared for by physical therapists (PT), occupational therapists (OT), speech-language pathologists (SLP), nurses, providers, and clinical social workers (CSW). Thus, each of these essential people and disciplines involved in caring for RBA, AVM, and hemorrhagic stroke survivors was educated on the support group details and recruitment and provided flyers to disseminate to potential participants.

## **Program Planning Team**

The creation of the program planning team was accomplished by the project lead and project site champion. To gain diversity within the committee, multiple people within many different disciplines from the hospital and neurosurgery office were either personally invited or emailed to participate. The project lead and project site champion selected these individuals based on their profession and experience. Numerous responses were received, and the positions were filled on a first-come-first-served basis. Members that served on the program planning team did so on a volunteer basis, and no pre-determined length of service was required.

The program planning team consists of eight multidisciplinary healthcare professionals. The project site champion, who is also the stroke program manager, functions as one of the two program planning team leaders. The other program planning team leader consisted of the project lead who is working towards his doctoral degree. The additional committee members consisted of two occupational therapists, three physical therapists, and a neurosurgeon. The committee member's educational backgrounds ranged from bachelor to doctoral degrees. The program planning team leaders are responsible for planning and facilitating program planning meetings.

All team members, including the leaders, functioned as content experts within their field and aided in planning sessions, facilitating sessions, and analyzing post-session data.

## **Project Goals and Outcome Measures**

The project aims are to create, implement, and sustain a support group that will provide its participants with an improved quality of life. Successful implementation will include participants gaining more knowledge concerning the current information on RBA, AVM, and hemorrhagic stroke. Participants will have the opportunity to develop better coping skills, have information on local services, feel less isolated, and develop new relationships. With a successful design and implementation, the sustainability of the support group will be enhanced.

To ensure the project is valid, has sustainability, and determine whether the group's goals and objectives are being met, the program and process will be evaluated. Two separate surveys were created to achieve this, one for the support group session participants and one for the program planning team members. The support group session participants consist of the RBA, AVM, and hemorrhagic stroke patients and their caregivers that attend each session. The program planning team members consist of the multidisciplinary team that plans, facilitates, and maintains the support group and attend the program planning meetings and support group sessions.

The support group session evaluation tool (Appendix B) was created to evaluate whether the program meets its objectives, goals, and purpose from the session participant's perspective. The program evaluation survey consists of 13 questions: demographic information, queries relating to program outcomes, and a suggestion section for participants to share feedback with the program committee. Participants will be provided time to reflect on the session and complete the evaluation tool after each session.

The program planning team evaluation tool (Appendix C) was created to evaluate whether the program process met its objectives, goals, and purpose from a program planning team member perspective. The tool consists of 11 questions related to demographics and program outcomes. The program planning team members are provided time to reflect on the program process and complete the program planning committee evaluation tool after each session.

To implement this project, the project lead met with key stakeholders, including the stroke program manager, neurosurgeons, the head of the neurology department, neurologists, neurointensivist, advanced practice nurses, physician assistant, and a neurology clinical nurse specialist to help ensure a multidisciplinary approach was taken in the creation of this group. Input from these individuals was used to aid in developing what information was essential to include and collect. Once the initial surveys were created, the project champion worked closely with the program planning team to further develop and refine the content.

## Description of the Methods and Measurement

Evaluating the process is an essential aspect of successful implementation and is key to ensuring program sustainability. The data obtained through the evaluation process informs the program planning team members whether the session was implemented as per the design and if any changes are warranted before the next meeting. The evaluations further provide a way for the program planning team members to track participant attendance, determine if the group is thriving and any concerns regarding the group process.

The program planning team's evaluation process is carried out monthly and occurs within one week of the previous meeting. During the evaluation process, data from the surveys are used along with the RE-AIM framework and PDSA cycles to help guide the improvement process.

Continually measuring the group's outcome will allow the group to refine itself and improve its participants' outcomes continually.

## Discussion of the Data Collection Process

To ensure that the data remains anonymous, no self-identifying questions were included in either survey. During the introduction and conclusion of each meeting, a member of the program planning team will inform participants of the survey to be completed and answer any questions that arise. After each session, members of the program planning team will disseminate the surveys to all the participants. Participation in the survey is voluntary, and time is allotted following each meeting to provide participants and members time to complete the survey. The completed surveys will be collected and evaluated by the program planning team at the end of each session, and data entered on an excel spreadsheet. Program participation, outcome, and demographic data will be assessed and displayed using columns, bar, pie, and line charts.

Current session data will be reviewed and compared to past session data by the program planning team monthly during the post-session program planning meetings. During the review process, the information collected will be discussed and used to guide the decision-making process and to improve the process. Future committee teams and program members will need to ensure the evaluation process remains intact to reflect new research and evidence-based practices.

#### **Implementation Plan**

The program planning committee began preparing for implementation during the July 29 program planning meeting. Additional program planning meetings were held on August 26 and September 9 and focused on preparing for the first support group session. The first support group session was held on September 17, 2020. Sessions were scheduled to occur on the third Thursday

of every month and held from 6:00 pm until 8:00 pm. Members of the program planning committee served as the group facilitators for the sessions.

Program guidelines are vital in creating and sustaining a supportive environment for the participants. To ensure a proper environment was created and maintained, the program planning committee developed group rules to govern each session (Appendix D). To help ensure participant buy-in, the participants were to create a group constitution during the first session that defines how the sessions will operate. The constitution would outline the expectations that all participants must adhere to and the expected conduct for all participants for the support group's duration. The constitution would include the group mission, group vision, membership, confidentiality, conflict resolution, and group leadership. Conducting the groups in an ethical matter is crucial, and having participant buy-in can further the bond among participants.

The session agenda (Appendix E) was initially created with findings from the literature, the Joe Niekro Foundation (JNF), and the multidisciplinary program planning team. Feedback from the meeting's first session would be used to develop future agendas. An open-style meeting agenda would be used to facilitate the sessions. The program planning team selected each session's guest speaker using input from the literature and the planning team members' expertise. Future guest speakers would follow the same selection process but would also incorporate participant recommendations.

In addition to the program planning team, other members involved in implementing the support group consisted of stroke center data abstractors and information technologies (IT). Data abstractors would be utilized to ensure the target population was being reached within the health system. The data abstractors audit this population's charts in real-time while they are hospitalized. A program flyer (Appendix F) was provided to the IT department within the health

system to aid in delivering information about the support group within the health system. The IT department uploaded the flyer into the electronic charting system (ECS) and made it accessible to everyone within the health system with access to the ECS. Once program implementation began, the charts of patients pertaining to this population had a note written on the front page of the patient's electronic medical record (EMR) by the data abstractors. The notes contained reminders to the staff about patient education on the support group sessions and informed them to attach the program information flyer to the discharge paperwork.

To effectively implement the program and recruit participants, vital departments within the health system and neurosurgery office were targeted with education and marketing materials. The program planning team assessed the two organizations and developed a list of most likely departments to interact with the target population while receiving care. Departments within the health system that serve this population include the neurological intensive care unit (NICU), neuroscience progressive care floors (NPC), social work, physical therapy (PT), occupational therapy (OT), speech-language pathology (SLP), inpatient rehabilitation, stroke center, and the Office of Spiritual Health.

The program planning team members were each tasked with educating specific departments on the list and followed up periodically as the program progressed. Each staff member within the selected hospital departments received an email from the program planning team with details on the support group, participant recruitment, where to direct questions, and the support group session flyer (Appendix F). Support group session flyers were provided to each department to disseminate to potential participants and post in high-visibility areas within their department.

The neurosurgery office consists of 12 neurosurgeons, two nurse practitioners (NP), one physician assistant (PA), registered nurses (RN), certified nursing assistants (CNA), and office staff. Critical staff within the practice were educated on the program details, participant recruitment, marketing materials and were provided with ongoing support to answer questions that arose during implementation. The additional office personnel were informed during their employee staff meeting and educated on who within the practice to contact for more details.

Outside the health system and neurosurgery office, support group information and advertising materials were provided to the JNF to place on their website and Facebook page. The JNF is a national advocate of RBA, AVM, and hemorrhagic stroke patients and helps connect survivors and caregivers to resources within their community. Partnering with the JNF provided a valuable partner that helped raise awareness for the group and provided another avenue for participant recruitment. JNF also shared their expertise with creating and sustaining support groups and provided the group with an email account for communicating with participants.

Facilitators to implementation included the multidisciplinary program planning team with support from essential local health organizations. The group was further supported by the University and the JNF. Another facilitator was the sessions' location that addressed potential barriers to participation such as transportation and disability.

Unfortunately, despite all of the planning, specific barriers could prevent proper program implementation. The very nature of suffering an RBA, AVM, or hemorrhagic stroke can place someone with new neurocognitive deficits that could make attending and sustaining membership within the support group difficult. This population's common conditions include depression, social withdrawal, and communication difficulties such as aphasia, dysarthria, dyspraxia. These

conditions can be refractory to the support group goals and make it difficult for them to participate within the group, even when they express interest (Castelein et al., 2015).

Inaccurate perceptions, knowledge, and stigmas attached to support groups pose additional barriers to sustaining a support group. Views held by patients, caregivers, or friends and family can influence whether a patient participates. Proper education on the appropriateness and usefulness of support groups can effectively overcome these misinformed attitudes and perceptions.

Barriers to access include many predisposing and enabling variables. Predisposing variables that could present as barriers include income, perceived cost-benefit ratio, coping, caregiver fulfillment, and group affiliation. Enabling variables that could present as barriers include social support, physical health, caregiver health, and living situation. As obstacles presented themselves, the program committee evaluated them and made the proper modifications to address the challenge.

#### **Timeline**

The support group idea initially came from assessing the local health system for needs relating to quality improvement (QI) initiatives. After a discussion with the stroke program coordinator in January of 2020, the idea to create a support group for RBA, AVM, and hemorrhagic stroke was identified. The idea was then presented to the university faculty, where it was approved to move forward.

Project exploration began in February 2020, followed by the literature review. To have an institutional partner in the creation of the project, an informal commitment with the stroke program manager was made in March 2020. Additional institutional support and resources were attained from contacting and partnering with the local outpatient neurosurgery practice and JNF

in April 2020. The stroke program manager formally committed in May 2020 to serve as the project site champion and co-leader for the program planning team. The project was approved and supported by the health system's Chief Nursing Officer in June 2020.

The planning phase began in May 2020 and continued through mid-August 2020. Members of the program planning committee were selected during mid-May, and the first official meeting was conducted on July 29. The project was reviewed by the University Institutional Review Board (IRB) in June, and the health systems nursing research council (NRC) and IRB in July, and both deemed the project as quality improvement.

Support group sessions were scheduled to occur on the third Thursday of each month starting in September. The program planning committee met monthly, approximately one week after each session, to discuss the past meeting and plan for the next session. See Appendix G for more details on the project timeline.

### Section IV. Results and Findings

#### **Results**

During the implementation period, the program planning team conducted three support group sessions and six program planning team meetings. The attendance rates of each support group session and program planning team meeting were tracked, as well as the number of Facebook members and email inquiries received by the group's email account. In addition to the measurements of attendance and interest in the program, the number of educated staff in each facility was also tracked to ensure appropriate dissemination of support group marketing materials.

After the planning stage and the pre-implementation program planning team meetings, it was expected that the program planning team meetings would be attended by at least 87.5% of the entire team. The initial support group session attendance was estimated at three to five participants, with each subsequent meeting increasing by one to two participants. After the implementation period, it was expected that the sessions would have around 50% of participants attending multiple sessions, and 50% would be participants attending their first session.

Participants joining the group's Facebook page and email inquiries were expected to be higher than the actual session attendance, with emails outnumbering Facebook members. Education of staff within each facility was set at 90% of total staff contacted.

The number of planning team meetings met the expected number of meetings to be held as outlined during the project's planning phase. During the program planning teams' meetings, seven (87.5%) of the eight members attended `four out of the six meetings, with two meetings reaching 100% attendance. The two meetings that did not meet the expected participation were attended by six (75%) of the eight planning team members.

The number of support group sessions to be conducted and evaluated during the implementation period was set to be three, and each occurred according to the plan. There was no participant attendance at any of the three sessions. However, each session was attended by an average of seven (75%) out of the eight program planning team members.

Each session had a varying degree of interest expressed through Facebook and email, but none were able to produce any participants. Two individuals emailed the group email account to inquire about the support group sessions. One email was received prior to the first session, and the second email was received before the second session. Facebook had a total of four members join. The first member joined two days before the second session, and the other three members joined in-between the second and third sessions.

During the planning stage, the program planning team identified 11 departments within the acute care center and two outpatient facilities as crucial locations to focus the program education. Prior to the first session, 237 staff members were educated. Eight out of the eleven (73%) acute care departments reached 90% or more staff educated. The three departments that did not reach the goal were between 65% to 87% of staff educated. The first outpatient facility reached 100% of staff educated, whereas the second outpatient facility with only 73% of staff educated.

#### **Outcomes Data**

During the planning phase, the support group session evaluation tool (Appendix B) and the program planning team evaluation tool (Appendix C) were created to gather data from each session. These tools were intended to obtain feedback from both the planning team members and the session participants. Each tool was designed towards evaluating the program process and evaluating whether its outcomes were being met. The data gathered from the evaluation tools

were to be used by the program planning team to improve the program's process and enhance the support group's sustainability. Since there were no attendees at these sessions, the evaluation tools were not used, and no outcome data were collected.

With a lack of data supplied from the evaluation tools, the program planning team relied solely on the RE-AIM framework and Plan-Do-Study-Act (PDSA) cycles to evaluate the process and outcomes. PDSA cycles were used monthly and provided a way for the planning team to implement and track changes to the process. The RE-AIM framework guided the planning team throughout the project and ensured the overall program outcomes were being met.

#### **Discussion of Major Findings**

The significant findings of this project result from the dedication put forth by the planning team members during the planning team meetings. The initial two pre-implementation planning team meetings occurred on August 26 and September 9. Additional planning team meetings were scheduled to occur after each support group session. Each meeting's goal was to evaluate the previous session, plan for the next session, and assess the process and outcomes using PDSA cycles.

## Pre-Implementation Planning Team Meetings

Pre-Implementation Planning Team Meeting One. The program planning team met on August 26 to discuss the support group's implementation plan. The discussion's main topic was to decide if the plan to conduct face-to-face sessions was still a viable option or if the sessions should move to an online forum. This topic was initiated due to the recent surge in COVID-19 cases among the community, concerns about bringing groups together, and the potential for COVID-19 cases to continue rising. Additional discussion focused on potential barriers to

implementation and included disseminating program information and program planning team attendance.

Educating the staff within the acute care center and the two outpatient facilities were the primary approach the planning team planned to recruit new participants. The planning team developed a roster to track staff who received education and guided future education needs. A goal of 90% of staff educated on each department and within the two outpatient facilities was decided, and education continued until the goal was achieved.

During the meeting, seven (87.5%) out of the eight planning team members were present. The lack of attendance by the entire team could hinder the group's decision-making capability due to not having the full multidisciplinary team present. The planning team developed a schedule for email reminders to be sent to the group to address the lack of attendance. In addition to the email reminders, an agreed-upon time and day of the week was chosen to conduct all future planning team meetings.

The initial goal of the support group during the planning stage was to conduct face-to-face sessions. However, during the planning stage, the COVID-19 pandemic spread throughout the world, and the uncertainty of what the future held for in-person meetings had to be considered. As planning progressed, it was determined that face-to-face meetings would not be an option. The planning team decided to move to an online forum with the goal of moving to face-to-face when the pandemic allowed. Multiple online meeting options were discussed, and mock support group sessions using Facebook Live, WebEx, and Zoom were scheduled. To help aid in the transition to online, other local well-established support groups that had already made the transition online were contacted to gain insight into their recommendations.

Pre-Implementation Planning Team Meeting Two. The program planning team met on September 9 to continue planning for the implementation of the support group. The main topic of conversation focused on discussing information gathered from researching potential online platforms and choosing an online platform for the support group sessions. In addition to selecting a platform, information and insights obtained from contacting other support groups that had moved to an online platform were discussed, as well as participant recruitment and staff education.

With the knowledge gained during the mock support group sessions and insight received from contacting other support groups, the program planning team discussed all online meeting options. At the conclusion of the discussion, the program planning team unanimously selected WebEx as the platform of choice to conduct the sessions. Additional factors that played into choosing the platform were related to being the most cost-effective, user-friendly, and versatile option.

To create an online community for the participants, and help facilitate relationship building, a group Facebook page was created. One of the program planning team members volunteered to champion the Facebook page and keep it up to date with meeting information and relevant content. Session reminder messages were scheduled to be sent monthly through Facebook to members of the Facebook page and email reminders to all participants that supplied their email addresses to the planning team. The support group Facebook page went live on September 10, 2021. It was advertised on the support group flyer (Appendix F), the Joe Niekro Foundation (JNF) website, and was searchable through Facebook.

#### **Program Planning Team Meetings**

Program Planning Team Meeting One. Support group session one was held on September 17, and the outcome of the session was evaluated on September 30. Due to the lack of attendance during the first session, the planning team reviewed the recruitment strategies and identified potential participation barriers. The key elements discussed focused on the technical challenges associated with using an online video conferencing system.

Technical difficulties for support group participants identified included the lack of a computer, lack of a webcam, computer literacy, internet connection, and learning how to use WebEx. An option offered to individuals who lacked the proper computer hardware and software was the ability to dial in by phone. To help alleviate technical concerns from deterring participation, the planning team posted links on the group's Facebook page that addressed topics such as general video chatting, online etiquette, and WebEx tutorials that demonstrated detailed directions on how to log into the sessions.

In addition to posting tutorials on the group's Facebook page, the planning team planned to dedicate the first 10 minutes of each session to a "how to use WebEx" tutorial. The tutorial focused on ensuring participants knew how to use the chat feature, muting and unmuting their microphones, and other elements needed to facilitate a good session. In addressing technical difficulties at the beginning of each meeting, the planning team aimed to improve attendance, participation, interaction, and sustainability.

If technical difficulties arose during the meeting or if participants were having trouble logging into a session, a member of the planning team was assigned the co-facilitator role and focused on assisting participants with technical issues or questions. To help participants more efficiently and not interrupt the session's flow, the planning team procured a phone number

through the acute care center to be used for participants to call and receive assistance. The phone number to call for help was provided to each participant with the WebEx invite and located on the group's Facebook page.

One key feature the planning team required of the selected platform was the ability to conduct multiple breakout groups within the main session. Initially, when the decision to switch to online sessions was made, the breakout groups remained as part of each session. However, with the planning team's continued discussion on decreasing possible technical and privacy issues, the breakout groups were removed from the agenda (Appendix E). This would be readdressed in the future when participant feedback could be used in the decision-making process.

During the implementation period, the planning team continued their conversations with the other local support groups initially consulted for recommendations. During many exchanges between the groups, nuances that tend to plague online support groups were identified. The planning team learned that longer online sessions tend not to go well with the participants. A lack of interest, concentration, and participation tends to occur in meetings over 1.5 hours. In addition to session length, using proper online etiquette and being respectful of the participant's time were also recurring themes during many of these discussions. The planning team considered all of the lessons learned from the other support groups and integrated them into this support group's development.

Program Planning Team Meeting Two. Support group session two was held on October 15, and the outcome of the session was evaluated on October 21. The conversation's main topic focused on the lack of participants and how to improve recruitment and attendance. Even though session two had no participants, the planning team had a small victory with the joining of the first Facebook member and a total of two email inquiries.

The Facebook member joined two days before session two and was quickly sent a welcome message that included an invite to join the next session. The initial message ended up sparking a conversation that lasted throughout the implementation period and gave the planning team valuable insight into possible barriers to attendance through a potential participant's perspective. The member's main barrier preventing them from attending the session was the start time being too early. With this new information, the program planning team discussed the pros and cons of changing the start time and ultimately decided to delay the start time by 30 minutes.

Before the second planning team meeting, two additional individuals joined the group's Facebook page. Welcome messages and invites were sent to those members as well. The increasing popularity of the Facebook page prompted the planning team to discuss ways to improve the use of Facebook and make it a more efficient recruitment tool. Before this, Facebook was being utilized to post updates about the sessions and general group information. The planning team determined that not regularly engaging with members and providing engaging content could hinder the recruitment potential of Facebook and could lead to members becoming disinterested in the group's page. To fully utilize the social media platform, the program planning team decided to create a more engaging page by interacting with the members more often and posting relevant content at least weekly.

Initially, recruitment efforts had been focused on the acute care center and the two outpatient facilities. Due to the lack of participation, the program planning team reevaluated the initial recruitment strategy. Members of the planning team reached out to potential participants within the acute care center to personally invite them to participate in the group and answer any questions. After multiple conversations with potential participants, it became apparent that the acute care population might not be ready to join a support group. When the potential participants were contacted, many were unsure of what had happened to them and unaware of what the future might hold. Some patients and families appeared to be in denial and had just started the initial grieving stages. It then became apparent that advertising and recruitment efforts needed to be spread more evenly among the community and not solely within healthcare facilities.

The planning team discussed many different options for reaching a broader audience and recruiting participants who might not frequent one of the targeted facilities. The planning team decided to reach out to the acute care facility and the two outpatient facilities and request contact information for current and past patients who met the support group's criteria. Once the contact information was received, a direct mail campaign would be conducted to notify potential participants of the new resource available to them.

Once the decision to conduct a direct mail campaign was made, the program planning team discussed how to fund the endeavor. Since the decision to move to an online platform was made, the discussion on financial support had ceased, and no funding was needed at the time. The group estimated an initial cost of around \$100 to cover the materials and postage to complete the initial round of letters (Appendix H). To help spread the cost out and not ask a single facility to donate all the funds, the three main facilities were asked to donate a portion of

the funds needed. In addition to the main facilities, the acute care facility's philanthropy office was asked to contribute.

Program Planning Team Meeting Three. Support group session three was held on November 19, and the outcome of the session was evaluated on November 25. The third support group session resulted in no participants joining and further reinforced the need to continue altering the recruitment strategy. During the planning team meeting, the focus was on the direct mail campaign's current state and the end of the project's implementation stage.

To help facilitate patient contact information requests and ensure that the new strategy did not violate the Health Insurance Portability and Accountability Act (HIPAA), the acute care facilities lead privacy officer and Department of Medical Records was contacted. Both the lead Privacy Officer and department of Medical Records examined the request and deemed it not a HIPAA violation, and permitted the planning team to proceed. Each of the facilities were then contacted by the planning team and informed of the planning team's new strategy and funding needs.

The acute care facility's philanthropy office responded to the planning team's request but was unable to provide funding directly to the support group. To gain potential funds, the request needed to come from a department director within the facility. Since the project site champion was also the stroke program coordinator, the project site champion volunteered to discuss the request with the neurosciences department director. At the conclusion of the third program planning team meeting, a decision from the neuroscience's director had yet to be received.

Even though the official project ended after program planning meeting three, the support group and planning team were set up to ensure it would be sustainable. The last major topic of discussion focused on the next steps for the support group. The planning team agreed to continue

perusing the new recruitment strategy and planning for the support group session into the foreseeable future.

#### **Section V. Interpretation and Implications**

#### **Cost-Benefit Analysis**

The main costs associated with successfully implementing this project were people, time, technology, and marketing. This project's expenses were kept to a minimum by partnering with an organization that allowed technology and marketing resources to be donated. Additionally, using volunteers to serve on the program planning team and guest speakers also helped minimize costs. The program planning team estimated the cost of implementing and hosting three support group sessions to be \$158. See Appendix H for more details on the project's budget.

The time required by each member of the planning team will vary on the role they fulfill and the type of group being managed. More time will be required of the planning team during the planning stage, which may lead to less time needed once the group has been established. Guest speakers were scheduled for a 20-minute block of time during the session. The last five minutes of the speakers' presentation were reserved for questions and open dialog.

Technology costs include the use of computers and online video conferencing software. For this project, the acute care centers' corporate WebEx membership allowed the support group to conduct the sessions and planning team meetings under their license. Using WebEx also gave the option to either call in using a phone or join via mobile application. Both options assisted in minimizing the cost of computer technology.

Marketing costs were initially limited to printed flyers, as all other avenues were digital. The acute care center provided free printing of the flyers that were distributed. As the project progressed and the recruitment strategy changed, the need for marketing funds also changed. During the implementation period, the need to mail letters (Appendix I) to potential participants within the community became apparent. However, during the project period, mailing the letters

never came to fruition, but the planning team planned to send approximately 100 letters to eligible participants.

An unexpected negative that occurred during implementation was low participation from the community. Due to the lack of attendance, more time was required of the program planning team to rethink the recruitment process and implement new ideas. Additionally, some of the new recruitment strategies would require funding to fulfill, which increased the support group's overall cost. The process of mailing letters to potential participants within the community was the most significant increase in time required from the planning team and had the most significant financial impact. The support group's Facebook page also required more time from the program planning team.

The costs associated with a reoccurrence or complication of a ruptured brain aneurysm (RBA), arteriovenous malformation (AVM), or hemorrhagic stroke can vary and significantly increase depending on the severity. When comparing acute care readmissions for hemorrhagic strokes to all other types of strokes, hemorrhagic strokes are the costliest, with an average cost of \$61,046, and have the most extended length of stay that averages 8.4 days (CostHelper Health, 2021; Lo et al., 2021). Additional procedures such as surgical clipping, endovascular embolization, surgical AVM removal, and stereotactic radiosurgery may be required and can significantly increase readmission costs (Mayo Foundation for Medical Education and Research, 2020). In addition to more procedures, these patients spend more days in the intensive care unit and suffer more complications such as pneumonia, urinary tract infections, and the need for a tracheostomy and percutaneous endoscopic gastrostomy (PEG) tube (Abdo et al., 2018). With this support group's implementation, reoccurrences and readmissions could be avoided, and much of the potential negative impacts to the community and survivors could be avoided.

In addition to the costs associated with an acute care readmission, the population this support group serves also suffers the worst functional outcomes at discharge than other forms of stroke. The poor functional state requires a more intense and lengthy rehabilitation plan and can significantly increase the event's overall financial burden (Abdo et al., 2018). Quang Vo and Hong Le (2019) reported the costs associated with one year of rehabilitation after being discharged from an acute rehabilitation program averaged \$17,081.

The financial impact of stroke in the United States is forecasted to increase 129% by 2030 and cost an estimated \$240.67 billion annually (Abdo et al., 2018). Other studies have shown a continued increase in stroke occurrence, with one study showing the occurrence of strokes doubling by 2050 (Luo et al., 2019). The low costs associated with implementing this project far outweigh the financial impact one event can have on the community and individual. With such high costs associated with just one reoccurrence of an RBA, AVM, or hemorrhagic stroke, this project's implementation can decrease the burden of stroke within the community and prevent hospital readmissions.

Overall, the organization received a good return on the investment it made into beginning this support group. Even though attendance was lacking during the support group's implementation period, the support group was established and designed with sustainability in mind. All members of the program planning team were volunteers, and the planning team meetings and the support group sessions were all scheduled to not interfere with anyone's work schedule. The support group's long-term outlooks continue to look positive as interest in the support group has increased. With this support group's continuation, the organization can expect to impact the overall patient experience, potentially decrease readmission rates, and lead to reduced costs associated with reoccurrence and complications.

## **Resource Management**

This project's success was due to the acute care facility's resources available to the program planning team. Being a Comprehensive Stroke Center, the acute care facility offered a large pool of highly qualified multidisciplinary individuals who had extensive expertise relating to the acute care and rehabilitation of the stroke patient population. The acute care facility provided members for the program planning team, guest speakers, marketing opportunities, and technology resources.

The request for program planning team volunteers yielded a total of 15 individuals. Out of the 15 total program planning team volunteers, eight were selected to join the team, and seven were placed on a waiting list to be contacted in the future. Since the planning team was strictly volunteers, no pre-determined length of time to serve was established, and members were free to leave the group at any time. The waiting list provided an opportunity to quickly replace members who decided to leave and with expertise to keep the planning team and sessions moving smoothly. Guest speakers were also selected from the same list of highly qualified individuals with extensive experience and interest.

The numerous disciplines and departments within the acute care facility were integral to success as they were the main points of contact for patients and caregivers during their hospital admission. Each staff member the patient or caregiver interacted with allowed for reeducation on the importance of continued support after being discharged and the availability of the support group. The program planning team could quickly gain access to the staff within the facilities, which made for an efficient marketing and education strategy.

The acute care facility provided the WebEx account for the planning team to use for support group operations and allowed the use of their Information Technologies (IT) department.

Having a free WebEx account helped keep program costs down and was a platform many of the program planning team members had previous experience within their daily roles. The IT department helped to procure the phone number used for planning team members and participants to use prior to and during each session to get assistance. The IT department served as a resource in answering questions regarding using the project site's website and electronic medical record (EMR) system.

The acute care facility provided the planning team with most of the resources needed to implement the support group. Throughout implementation, planning team meetings identified new ideas and resources that could potentially improve the process. When a new plan was identified, the planning team was able to work with the project site to identify the appropriate individuals needed to help address barriers.

## **Implications of the Findings**

The creation and implementation of a stroke support group is a cost-effective way for the organization to help its community decrease the overall burden of stroke and meet its goals and obligations as a quality healthcare provider. By participating in the interdisciplinary program planning team, members will gain valuable insight and experience through interactions with disciplines and individuals they otherwise would have little to no contact with. The support group participants will benefit from attending the sessions by gaining a resource that was not previously available to them to improve their overall wellbeing.

#### Implications for Patients

With this support group's creation, survivors and caregivers will have additional resources available to help them navigate life after an RBA, AVM, or hemorrhagic stroke. Available resources can support and lead to increased survivor and caregiver satisfaction, decrease the financial impact of recovery, and fewer medical complications. Survivors and their caregivers could have reduced social isolation and depression rates by joining a group focused on building relationships through shared experiences.

Members of the group will gain a network that aims to deliver the appropriate psychosocial support needed and connect them with healthcare professionals seeking to help improve their outcomes post-discharge. Through participation within the group, survivors will gain the ability to decrease complications that could increase the rehabilitation phase's duration and could lower reoccurrence and readmission rates. Caregivers can gain valuable insights into what the survivor is experiencing and learn ways to assist in caring for the survivor through their unique perspective. Survivors and caregivers will gain practical knowledge and education to help them cope with the stressors associated with post-stroke life and attain better outcomes.

Through fewer complications and a potentially shorter and more efficient rehabilitation, participants can rejoin the workforce sooner and have less of a need for additional healthcare resources. By decreasing the amount of healthcare resources required and time out of work, both survivors and their caregivers will see much less of a financial impact due to a hemorrhagic stroke. Participating in the support group sessions fosters a better transition from the acute care center to rehabilitation center and rehabilitation center to rejoining the community as active members.

## Implications for Nursing Practice

Nursing practice will be enhanced through direct participation in the support group and having additional evidence-based resources to offer the population they serve. Nurses will gain valuable insight through interacting directly with survivors, caregivers, multidisciplinary planning team members, and guest speakers. The support group also offers nursing another avenue to disseminate practical health education to a population that might not seek medical care from providers.

Advance practice nurses will gain valuable experience from the sessions that can improve current and future patients' outcomes and provide another evidence-based intervention for their patients. The support group offers a way to increase the continuity of care from acute care through recovery. With participation, the advanced practice nurse will have an opportunity to gain knowledge about interdisciplinary teams and how to lead them. Advance practice nurses can take a leadership role and provide expertise in offering and supporting their patients to participate in a support group.

## Impact for Healthcare System(s)

The healthcare system will be impacted through a continued effort to decrease the community's incidence and burden of stroke. The support group can reduce readmission rates, decrease emergency department visits, improve patient satisfaction, and ultimately decrease the length of stay within the acute care centers. With a potential for a decrease in complications and reoccurrences, resources that would have been allocated for this population could be reallocated to other areas of need. The minimal amount of resources the healthcare system invests in continuing this support group far outweighs the potential financial and physical impact.

With this support group's continuation, the healthcare system can fulfill its mission and work towards goals to improve its community's health. Healthy People 2020, Healthy North Carolina 2020, the Institute for Healthcare Improvement's Triple Aim framework, and the World Health Organization all include goals to improve health and decrease the overall incidence and burden of stroke. Through the continued commitment to sustain this support group, the healthcare facilities can align themselves with these goals and do their part to ensure their community is being served appropriately and help reach the goals that have been set forth.

The continuation of Comprehensive Stroke Center certification requires the organization to demonstrate its commitment to increasing the standards of care, improving patient outcomes, and provide resources that address all aspects of the continuum of care. This support group can help meet the requirements needed to continue recertification in the future. Its continuance shows that the healthcare system is dedicated to improving patient outcomes and clinical excellence.

#### **Sustainability**

Before beginning this project, the project lead and site champion discussed resources the community lacked and programs the project site desired to create. As a result of the discussion, this project was chosen due to the community's need and the support offered from the project site. Selecting a project that had organizational buy-in from the beginning would increase the likelihood of its sustainability.

Continuing this support group is a cost-effective way to provide community outreach and improve outcomes. The organization plans to continue the support group indefinitely, with the hopes of transitioning to face-to-face meetings once COVID-19 has subsided to allow for inperson meetings to resume. Leadership within the participating facilities has continued to pledge support for the support group and recognize the benefit to the community and organization.

The organization can continue this project as it requires minimal funding and relies on volunteers to run and manage the sessions. Once the transition to face-to-face meetings occurs, the support group will continue to be a low-cost intervention. The sessions will occur within the local acute care center as it is convenient and easily accessible, and the available space is free of charge. Sponsorship can be attained through drug and device companies and will allow for catering of meals, financial support, and educational materials.

The project was designed to continue to function with minimal organizational resources. Planning team members were selected with sustainability in mind, and three co-leaders were chosen initially. Two co-leaders served as the group's primary leaders, and the third co-leader was an active member of the planning team that kept up to date on what the two main co-leaders were doing. The third co-leader position was designed to transition to a primary co-leader role if one of the main two co-leaders decided to step down.

As the support group becomes more established, the program planning team's roles will become available for participants to volunteer to serve as planning team members. The long-term plan is for participant volunteers to serve on the program planning team with potential vital roles and responsibilities, including managing the group's Facebook page and responding to emails. The addition of participant volunteers will further decrease the healthcare facility's resources and increase sustainability by giving participants more ownership in the group.

#### **Dissemination Plan**

Many individuals and organizations beyond the stroke community could benefit from the knowledge gained from the project. Anyone considering creating a new support group or transitioning an existing support group to an online platform would benefit. Sharing the

information acquired through this project will be done by abstract and manuscript submission, conference presentations, and presenting to the university and the sponsoring organization.

An abstract for manuscript submission will be submitted to three journals within the neurological community to help share this project with a broader audience. The project lead will submit abstracts to the following journals: Stroke, Topics in Stroke Rehabilitation, and the Journal of Stroke and Cerebrovascular Diseases. All three journals work on a continuous submission basis and have no set deadlines associated with the submission dates. The Stroke journal indicates that once a manuscript is submitted, it should be evaluated within two weeks. The other two journals indicate that new content is reviewed continuously.

As part of this project's requirements, a poster and oral presentation highlighting the project's main details were created. The poster and oral presentation were presented to the university using an online platform in April of 2021. In addition to presenting the poster and oral presentation, a copy of the final written project was uploaded to the university's electronic repository of scholarly work.

Ensuring the sustainability of this support group was a primary objective of the project lead. After the poster was presented to the university, the poster was then presented to key stakeholders within the project site and the program planning team. One of the goals in presenting at the project site was to gain continued support for the intervention and increase its awareness within the community.

Two conferences were identified as being a beneficial target group for the dissemination of this project. The American Stroke Association (ASA) and American Heart Association (AHA) International Stroke Conference, and the State-of-the-Science Stroke Nursing Symposium will have abstracts submitted. Since the 2021 abstract submission period has ended for both

conferences, the abstract will be submitted once the 2022 abstract submission period is announced. With the uncertainty of how conferences will be delivered in 2022, an electronic version of the poster with a recorded presentation will be submitted if an online format is used, and a poster presentation will be delivered if the presentation is face-to-face if accepted.

#### **Section VI. Conclusion**

#### Limitations

As the project progressed through the implementation phase, two main limitations became evident. One limitation identified was the lack of participation during the support group sessions. The second limitation was the time constraints involved with the deadlines that the project was required to meet.

The lack of participation during the implementation phase prevented the use of the participant evaluation tool. Not evaluating the program process and outcomes from the participant's perspective prevented the program planning team from including valuable input into discussion on improving the process and ensuring sustainability. Due to the inability to collect information with the evaluation tools, the program planning team relied solely on the three Plan-Do-Study-Act (PDSA) cycles conducted during the implementation phase.

Many promising ideas aimed at enhancing participation came from using the PDSA cycles by the program planning team. However, the project's implementation phase was limited to three months and only allowed three PDSA cycles to be performed. The time constraints during the implementation phase made it challenging to implement and evaluate many of the promising ideas. Future programs could benefit from having more time during the implementation phase to implement and evaluate changes developed through PDSA cycles and participant feedback.

Many barriers were identified that could have contributed to the lack of session attendance. The main barrier identified was the COVID-19 pandemic that started shortly after project planning began. The pandemic produced many challenges to implementing a support group and ultimately changed the delivery method from face-to-face to online. Successful

support groups rely strongly on participant socialization and building trusting relationships.

Using online meeting platforms can hinder the relationship-building ability and thus contribute to not achieving the expected outcome.

Weather also presented as a barrier. On the day of the first session, a tornado passed through the local community and caused widespread electricity and internet outages. The session went on as planned, as many planning team members were unaware of the lack of power and internet affecting parts of the community. During the days following the session, the planning team learned that the natural disaster impacted the session's attendance and prevented the two participants that had emailed the planning team from attending the session.

Another barrier was accessing the contact information of potential participants from participating organizations. Attaining approval from three separate organizations and ensuring the requests were ethical required more time than what the planning team had anticipated. Once organizational support was achieved, procuring the desired information from each organization continued to be a time-consuming endeavor. The contact information could not be obtained during the project time frame and subsequently did not allow the direct mail campaign to be executed.

#### **Recommendations for Others**

During the development, implementation, and evaluation of this project by the planning team, many recommendations for future support groups were identified. One key area to successful implementation and sustainability involves disseminating advertising materials and the recruitment of participants. Before implementing a new support group, it is recommended that advertising and participant recruitment begin as early as possible. Building a participant base

prior to the first session can provide participant feedback to the planning team and ensure a large enough cohort of people will be present to conduct the session.

To help ensure everyone throughout the community is aware of the new support group, it is recommended that advertising material not be focused solely on healthcare facilities. Some potential participants may have minimal contact with health care providers and thus would not learn about the new opportunities. The contact information of current and past patients can be obtained from the facilities and used for a direct mail campaign. Other areas of potential advertising will depend on resources and organizations available within the community. Local newspapers, city calendars, community centers, rehabilitation centers, and churches tend to offer free advertising for support groups and can prove to be an effective means of program advertising.

When procuring contact information to contact potential participants through a direct mail campaign, focusing on one facility at a time could speed the process up and make it more efficient. Instead of having multiple planning team members concentrate on different facilities, they could all work together to accomplish the same goal. Being able to speed this process up could impact attendance in a shorter amount of time.

Since the support group ultimately aims to benefit the participants, including their feedback can help ensure the process is compatible with participants' needs. Additionally, participant feedback informs the planning team that the group's intended outcomes are being met and if changes need to be made. Including participants in deciding the time, date, and frequency of the sessions will ensure the sessions are convenient and appropriate for the targeted population. Participant feedback can also help the planning team with agenda planning, guest speaker selection, and desired activities. As the support group becomes established, participants

can also help take over some of the groups' administrative tasks and participating in the program planning team. Having insight into the participants' needs and desires can help identify barriers that might have otherwise gone unknown.

The creation of an engaged multidisciplinary program planning team is imperative to a successful support group. Broadening the search for members beyond a single organization and asking for volunteers will help candidates feel that participation is not a burden. Including members from numerous disciplines will provide valuable insight from various aspects and ensure that program outcomes are met.

To ensure the support group has the support needed to be implemented and ensure its sustainability, organizational and leadership buy-in and support are essential. As the support group progresses, new obstacles that arise could require additional resources that are not readily available to the program planning team. Having a support structure in place will help overcome the challenges in a timely and efficient manner.

Using an online meeting platform is unique and requires additional skills to conduct sessions successfully. Having session facilitators who know how to properly use the online platform and technology to facilitate its use is vital to running each session. Meeting facilitators should be comfortable using the meeting platform and ensure their computer hardware is appropriate for conducting sessions before initiating live sessions. Mock sessions conducted by the program planning team are an excellent way to practice and ensure technology is working appropriately.

As the creation and implementation of this support group progressed, Facebook became increasingly crucial for group advertising and participant engagement. It is recommended to take full advantage of social media to advertise and engage with potential and current participants.

Social media is a valuable tool for building relationships and promoting socialization among participants and planning team members.

While using Facebook or other social media platforms, it is vital to keep participants engaged by posting relevant content and updating it regularly. Interacting with participants who join or express interest in the social media page can be an effective way to begin building relationships. Having a program planning team member manage the group's social media will allow for a consistent approach and ensure everyone is contacted promptly.

## **Recommendations Further Study**

Initiating a support group during a pandemic that limits face-to-face contact is unprecedented. Online meeting platforms are not new and were in use before the pandemic. However, there is a lack of information on best practices associated with creating and sustaining online support groups. The lack of resources leaves a significant gap in knowledge and offers many areas to explore in the future.

To help ensure new support groups can thrive in an online environment, an evaluation into strategies that improve participant recruitment and group marketing would be beneficial. Identifying where and how to advertise, whether it be online, more traditional methods, or a combination of both, would help guide future marketing efforts. Additionally, evaluating the effectiveness of direct-mail campaigns, email blasts, and healthcare referrals could aid in appropriating resources and identifying methods that will produce the most significant impact.

The use of social media to recruit and conduct support groups appears to be a promising tool. Social media's abilities make it an effective way to bring a continuous presence to a support group. Frequently updating content and interacting with members could lead to more engaged participants. Social media could also allow participants to learn more about each other and

interact outside of the group. Having a way for participants to interact outside of an online session could foster trusting relationships and create bonds that otherwise might not be possible. Besides creating a space for participants to interact, social media platforms could be a seamless way to transition into online support group sessions.

The features and abilities of electronic medical record (EMR) systems are an everchanging environment within healthcare. Taking full advantage of the many resources that an
EMR can provide could lead to an effective way of advertising a support group within healthcare
facilities. Including best practice advisory popups when a chart is accessed, support group
information within care plans and discharge papers, and adding educational tasks to the staff
worklists could prove to be an effective way of disseminating and reinforcing program
information.

Online support groups offer many challenges that may not exist within the more traditional face-to-face type sessions. As technology and social media continue to progress, these challenges could diminish and open new opportunities to introduce online support groups.

Internet-based support groups also can reach individuals who cannot attend a face-to-face meeting due to distance, disability, or other reasons. Social media and technology are continuing to have an increased presence within our society. Additional studies are needed to help determine the most effective way to deliver support and form trusting relationships in an online environment.

Future studies are needed to evaluate online support groups' effectiveness and compare them to the more traditional face-to-face support groups. Assessing patient outcomes will also be necessary and could help to justify their creation and organizational buy-in. To further determine the effectiveness of online support groups, looking for a decline in hospital readmission rates and

emergency department visits after implementation would be a strong indicator of program success. Having data showing the benefits and positive outcomes associated with online support groups could increase attendance and sustainability.

#### References

- Abdo, R., Abboud, H., Salameh, P., Jomaa, N., Rizk, R., & Hosseini, H. (2018). Direct medical cost of hospitalization for acute stroke in Lebanon: A prospective incidence-based multicenter cost-of-illness study. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*. https://doi.org/10.1177/0046958018792975
- Amatangelo, M., Prvu-Bettger, J., Collins, K., Jackson Barry, B., Miller, E., Nguyen, M., ... Lombardi-Hill, D. (2017). Advancing stroke recovery through social and emotional support. *Stroke*, 48, 373. <a href="https://doi.org/10.1161/str.48.suppl\_1.tp373">https://doi.org/10.1161/str.48.suppl\_1.tp373</a>
- American Counseling Association. (2014). 2014 ACA code of ethics. https://www.counseling.org/resources/aca-code-of-ethics.pdf
- American Stroke Association. (n.d.). Successful stroke support groups. Retrieved April 27, 2020, from <a href="https://www.stroke.org/-/media/stroke-files/help-and-support/support-group-leaders-guide-ucm\_309688.pdf?la=en&hash="artificial-en&hash="https://www.stroke.org/-/media/stroke-files/help-and-support/support-group-leaders-guide-ucm\_309688.pdf?la=en&hash="artificial-en&hash="https://www.stroke.org/-/media/stroke-files/help-and-support/support-group-leaders-guide-ucm\_309688.pdf?la=en&hash="artificial-en&hash="https://www.stroke.org/-/media/stroke-files/help-and-support/support-group-leaders-guide-ucm\_309688.pdf?la=en&hash="artificial-en&hash="https://www.stroke.org/-/media/stroke-files/help-and-support/support-group-leaders-guide-ucm\_309688.pdf?la=en&hash="artificial-en&hash="https://www.stroke.org/-/media/stroke-files/help-and-support/support-group-leaders-guide-ucm\_309688.pdf?la=en&hash="https://www.stroke.org/-/media/stroke-files/help-and-support/support-group-leaders-guide-ucm\_309688.pdf?la=en&hash="https://www.stroke.org/-/media/stroke-files/help-and-support/support-group-
- American Stroke Association. (2017). Advancing stroke recovery through social and emotional support. <a href="https://www.stroke.org/-/media/stroke-files/stroke-resource-center/recovery/provider-focused/advancing-stroke-recovery-through-emotional-and-social-support-ucm\_492297.pdf?la=en&hash=2F86D8DFF089899BA4</a>
  D8467EB146A17633D8E073
- American Stroke Association. (2020). *Starting a support group*. https://www.stroke.org/en/help-and-support/support-group-leader-resources/starting-a-support-group

- Aziz, Z., Riddell, M. A., Absetz, P., Brand, M., & Oldenburg, B. (2018). Peer support to improve diabetes care: An implementation evaluation of the Australasian peers for progress diabetes program. *BMC Public Health*, *18*. http://dx.doi.org/10.1186/s12889-018-5148-8
- Brain Aneurysm Foundation. (2019). *Support Groups*. <a href="https://bafound.org/recovery/support-groups/">https://bafound.org/recovery/support-groups/</a>
- Brooker, D., Chattat, R., Evans, S., Evans, S. C., Farina, E., Henderson, C., Meiland, F., Rymaszewska, J., Dorota, S., Urbańska, K., Atkinson, T., Bray, J., d'Arma, A., Gamberini, G., Hendriks, I., Rehill, A., Lea Saibene, F., Scorolli, C., Orrell, M., . . . Dröes, R. (2017). [P4–544]: Meetingdem reporting on the implementation, effectiveness and cost-effectiveness of the dutch meeting centres supports programme for people living with dementia and family carers in three european countries. *Alzheimer's & Dementia*, *13*(7), P1560. https://10.1016/j.jalz.2017.07.707
- Castelein, S., Bruggeman, R., Davidson, L., & Gaag, M. (2015). *Creating a supportive*environment: Peer support groups for psychotic disorders.

  https://academic.oup.com/schizophreniabulletin/article/41/6/1211/2526048
- Centers for Disease Control and Prevention. (2020, February 19th). *Stroke*. https://www.cdc.gov/stroke/index.htm
- Chesman, N., Mackland, A., & McWilliams, L. (2017). Developing a support service for teenage and young adult cancer survivors with osteonecrosis. *Cancer Nursing Practice* (2014+), 16(6), 36. http://dx.doi.org/10.7748/cnp.2017.e1425
- Childers, C., & Rutherford, K. (2017). The power of community for post-TBI life. *ASHA Leader*, 22(11), 30-32. https://search.proquest.com/docview/1952360114? accountid=10639

- Cone Health. (2020a). FY2020 Hemorrhage Volumes. [Data file]. Cone Health: Stroke Center
- Cone Health. (2020b). *Moses Cone Hospital*. https://www.conehealth.com/locations/moses-cone-hospital/
- CostHelper Health. (2021). *Stroke treatment cost*. https://health.costhelper.com/treating-stroke.cost.html.
- Evans, S., Evans, S., Booker, D., Henderson, C., Szcześniak, D., Atkinson, T., Bray, J., Amritpal, R., Saibene, F., d'Arma, A., Scorolli, C., Chattat, R., Farina, E., Urbańska, K., Rymaszewska, J., Meiland, F., & Dröes, R. (2020). The impact of the implementation of the Dutch combined Meeting Centres Support Programme for family caregivers of people with dementia in Italy, Poland and UK. Aging & Mental Health, 24(2), 280–290. doi: 10.1080/13607863.2018.1544207
- Gabbe, P. T., Reno, R., Clutter, C., Schottke, T. F., Price, T., Calhoun, K., & Sager, J. (2017).

  Improving maternal and infant child health outcomes with community-based pregnancy support groups: Outcomes from Moms2B Ohio. *Maternal and Child Health Journal*,

  21(5), 1130+. <a href="https://link.gale.com/apps/doc/A550918943/HRCA?u">https://link.gale.com/apps/doc/A550918943/HRCA?u</a>
  =ncliveecu&sid=HRCA&xid=f54ae7c2
- Im, E. O., Ji, X., Zhang, J., Kim, S., Lee, Y., Chee, E., Chee, W., Tsai, H. M., Nishigaki, M., Yeo, S. A., Schapira, M., & Mao, J. J. (2016). Issues in developing and evaluating a culturally tailored internet cancer support group. *Computers, Informatics, Nursing:*CIN, 34(10), 462–469. https://doi.org/10.1097/CIN.00000000000000261
- Institute for Healthcare Improvement. (2020). Initiatives.
  - http://www.ihi.org/Engage/Initiatives/TripleAim/Pages/default.aspx

- Institute for Healthcare Improvement. (2021). *How to improve*.

  http://www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementTestingChang
  - es.aspx
- Jaipakdee, J., Jiamjarasrangsi, W., Lohsoonthorn, V., & Lertmaharit, S. (2015). Effectiveness of a self-management support program for Thais with type 2 diabetes: Evaluation according to the RE-AIM framework. *Nursing & Health Sciences*, *17*(3), 362-369. doi:10.1111/nhs.12198
- Joe Niekro Foundation. (2020a). *Our Mission*. <a href="https://www.joeniekrofoundation.com/about-us/who-we-are/">https://www.joeniekrofoundation.com/about-us/who-we-are/</a>
- Joe Niekro Foundation. (2020b). *Support Groups*. <a href="https://www.joeniekrofoundation.com/patient-caregiver-support/support-groups/">https://www.joeniekrofoundation.com/patient-caregiver-support/support-groups/</a>
- Lo, J., Chan, L., & Flynn, S. (2021). A systematic review of the incidence, prevalence, costs, and activity and work limitations of amputation, osteoarthritis, rheumatoid arthritis, back pain, multiple sclerosis, spinal cord injury, stroke, and traumatic brain injury in the United States: A 2019 update. *Archives of Physical Medicine and Rehabilitation*, 102(1). https://doi.org/10.1016/j.apmr.2020.04.001
- Lund, A., Melhus, M., & Sveen, U. (2018). Enjoyable company in sharing stroke experiences; lifestyle groups after stroke. *Scandinavian Journal of Occupational Therapy*, 25(2), 127–135. https://doi.org/10.1080/11038128.2017.1341958
- Luo, L., Xu, X., Jiang, Y., & Zhu, W. (2019). Predicting intracerebral hemorrhage patients' length-of-stay probability distribution based on demographic, clinical, admission diagnosis, and surgery information. *Journal of Healthcare Engineering*, 2019. https://doi.org/10.1155/2019/4571636

- Malini, M. H. (2015). Impact of support group intervention on family system strengths of rural caregivers of stroke patients in India. *Australian Journal of Rural Health*, 23(2), 95-100. https://10.1111/ajr.12126
- Mayo Foundation for Medical Education and Research. (2020). *Stroke*. Mayo Clinic. https://www.mayoclinic.org/diseases-conditions/stroke/diagnosis-treatment/drc-20350119.
- McGuire, K. B., Stojanovic-Radic, J., Strober, L., Chiaravalloti, N. D., & DeLuca, J. (2015).

  Development and effectiveness of a psychoeducational wellness program for people with multiple sclerosis: Description and outcomes. *International Journal of MS Care*, *17*(1), 1–8. https://doi.org/10.7224/1537-2073.2013-045
- Melnyk, B. M. (2016) Level of evidence plus critical appraisal of its quality yields confidence to implement evidence-based practice changes. *Worldviews on Evidence-Based Nursing*, 13(5). https://doi.org/10.1111/wvn.12181
- National Institute of Neurological Disorders and Stroke. (2019). *Stroke Information Page*. <a href="https://www.ninds.nih.gov/Disorders/All-Disorders/Stroke-Information-Page">https://www.ninds.nih.gov/Disorders/All-Disorders/Stroke-Information-Page</a>
- NC Department of Health and Human Services. (2019). *Healthy North Carolina 2020: Focus areas, objectives, and evidence-based strategies summary tables*. https://publichealth.nc.gov/hnc2020/foesummary.htm
- Pinxsterhuis, I., Hellum, L. L., Aannestad, H. H., & Sveen, U. (2015). Development of a group-based self-management programme for individuals with chronic fatigue syndrome: A pilot study. *Scandinavian Journal of Occupational Therapy*, 22(2), 117–125. https://doi.org/10.3109/11038128.2014.985608

- Quang Vo, T., & Hong Le, P. (2019). Post-stroke rehabilitation cost with traditional therapy:

  Evidence from a public hospital. *Journal of Pakistan Medical Association*, 69(6).

  https://link.gale.com/apps/doc/A600046135/HRCA?u=ncliveecu&sid=HRCA&xid=ebd7

  f093
- RE-AIM. (2020). Frequently asked questions. http://www.re-aim.org/about/frequently-asked-questions/
- Roush, S., Monica, C., Pavlovich, D., & Drake, R. (2015). Community engagement research and dual diagnosis anonymous. *Journal of Dual Diagnosis*, 11(2), 142-144. doi: 10.1080/15504263.2015.1025214
- Sullivan, J., Adjognon, O., Engle, R., Shin, M., Afable, M., Rudin, W., White, B., Shay, K., Lukas, C. (2018). Identifying and overcoming implementation challenges: Experience of 59 noninstitutional long-term services and support pilot programs in the Veterans Health Administration. *Health Care Management Review*, *43*, 193-205. https://doi.org/10.1097/HMR.0000000000000152
- US Department of Health and Human Services. (2020). *Heart disease and stroke*.

  <a href="https://www.healthypeople.gov/2020/topics-objectives/topic/heart-disease-and-stroke/objectives">https://www.healthypeople.gov/2020/topics-objectives/topic/heart-disease-and-stroke/objectives</a>
- Warshaw, H., Hodgson, L., Heyman, M., Oser, T. K., Walker, H. R., Deroze, P., Rinker, J., Litchman, M. L. (2019). The role and value of ongoing and peer support in diabetes care and education. *The Diabetes Educator*, 45(6), 569–579. https://doi.org/10.1177/0145721719882007

- Watson, E., Lambert, M., & Machin, K. (2016). Peer support training: Values, achievements and reflections. *Mental Health Practice* (2014+), 19(9), 22. http://dx.doi.org/10.7748/mhp.19.9.22.s20
- White, T, & Schweickert, P. (2015). Assessing Effects of Stroke Support Groups on Social Integration in Acute Stroke Patients. *Stroke*, 45(1).
- World Health Organization. (2016). Stroke: A global response is needed. *Bulletin of the World Health Organization*, 94(9), 633–708. doi: <a href="http://dx.doi.org/10.2471/BLT.16.181636">http://dx.doi.org/10.2471/BLT.16.181636</a>
- Zavoda, E. (2015). The evolution of a low vision support group. *OT Practice*, 20(13), 19–20. https://search.proquest.com/docview/1698280067?accountid=10639

# Appendix A

## **Literature Matrix**

Authors	Year Pub	Article Title	Theory	Journal	Purpose and take home message	Design/ Analysis /Level of Evidence	IV DV or Themes concepts and categories	Instr. Used	Sample Size	Sample method	Subject Charac.	Comments/critique of the article/methods GAPS
Roush, Monica, Pavlovich & Drake	2015	Community Engagement Research and Dual Diagnosis Anonymous	Community- based participation	Journal of Dual Diagnosis	Community engagement research requires frontline participants, community members, and professional collaborators to overcome multiple barriers.	Level IV Descriptive	IV: Community engagement, community partners DV: Improved outcomes	Qualitative interviews, focus groups	Ongoing research program	Dual Diagnosis Anonymous	The Oregon Department of Corrections and the Oregon State Hospital	Describes implementation of a community peer support program for people with co-occurring mental illness and substance use disorders.
Chesman, Mackland, & McWilliams	2017	Developing a support service for teenage and young adult cancer survivors with osteonecrosis.	Coping factors in relationship to teen survivors with osteonecrosis	Cancer Nursing Practice	This article explains how and why the group was created, and describes themes frequently discussed by the young people in the group and the subsequent projects.	Level IV Descriptive	IV: Support and coping strategies DV: Improved self esteem and outcomes	self-completed, written questionnaire consisted of eight closed questions about information provision, perceived coping and the effect of osteonecrosis on several physical and mental domains, shown to be important in quality of life assessments for other cancer-related symptoms.	6	The support group, based in the TYA unit, was advertised through the center's TYA Facebook page, and by emails and text messages to those with osteonecrosis known to the TYA service. At the time this included 15 young people, 12 of them with ALL, one with Hodgkin lymphoma, and two who had had stem cell transplants. Six individuals (40%) agreed to attend the first group.	four females and two males, aged between 21 and 24	Recommendations for support group recruitment and the development of appropriate support and follow-up systems.  Explored the experiences of young people with osteoneorosis through a questionnaire, and discussions at a support group Revealed complex and diverse effects of the condition on various aspects of life. Helped confirm the need for the support group.
McGuire, Stojanovic- Radic, Strober, Chiaravalloti & DeLuca	2015	Development and effectiveness of a psychoeducational wellness program for people with multiple sclerosis: description and outcomes	Biopsychosocial model	International Journal of MS Care	Support groups are effective in improving self- reported depression, anxiety, perceived stress, and pain. Also experienced an increase in positive affect.	Initial pilot study	IV: Well-being and quality of life DV: Improvements in depression, anxiety, and overall mental health.	Participants completed a total of eight questionnaires, six of which were part of the Multiple Sclerosis Quality of Life Inventory,24 at baseline and follow-up.	72	Seventy-two participants completed the study, of which 61 were in the treatment group and 11 in the control group.	Average age of 50, 14.34 years education, 135.07 months with disease, 88.4% female. All participants had a clinically definite MS diagnosis per McDonald criteria. All participants were able to speak, read, and write in English.	The biopsychosocial model of disease takes into account the multifaceted nature of chronic illness and is often applied in the field of MS. The complex nature of MS requires a multidimensional approach to treatment. A psychoeducational wellness program is an effective supplement to traditional medical managreement to improve the overall quality of life and well-being of individuals with MS. The aim of a wellness program is to provide a supportive learning environment focused on teaching people with MS how to manage disease-related challenges in the physical, psycho-logical, social, and spiritual domains that affect their quality of life.

Authors	Year Pub	Article Title	Theory	Journal	Purpose and take home message	Design/ Analysis /Level of Evidence	IV DV or Themes concepts and categories	Instr. Used	Sample Size	Sample method	Subject Charac.	Comments/critique of the article/methods GAPS
Pinxsterhuis, Hellum, Aannestad, & Sveen	2015	Development of a group- based self- management programmed for individuals with chronic fatigue syndrome: a pilot study	Self-efficacy theory	Scandinavian Journal of Occupational Therapy	The aim of the study was to develop a group-based self-management program for individuals with chronic fatigue syndrome by using the participants' experiences with the initial version of the program, which intends to promote coping with the illness in a primary healthcare setting.	Level IV Descriptive	The interviews were analyzed using thematic analysis	Developed a framework for developing and evaluating complex interventions to improve health. Focusgroup interviews were applied. The interviews were analyzed using thematic analysis.	6	The participants were invited to participate in focus-group interviews to share their experiences after taking part in the initial programmed. Focus-group interviews were chosen as group dynamics between the participants may generate a larger and richer range of ideas than individual interviews	The mean age of the participants was 38.7 years (range 28–46) and they were diagnosed with CFS from one week to seven years (mean 2.3 years) ago. Only one of the participants was working. Four had higher education, and five were married or lived with a partner.	The program was found to be feasible, although several modifications regarding the content and practical organization of the program were proposed. In line with the participants' experiences, the final self-management program was developed, which includes short presentations of eight topics, exchange of experiences among participants, goal-setting, construction of action plans, and relaxation exercises, in addition to a meeting for relatives.
Lund, Melhus & Sveen	2018	Enjoyable company in sharing stroke experiences; - lifestyle groups after stroke	Sharing similar experiences and peer- to-peer support	Scandinavian Journal of Occupational Therapy	The aim of this study was to explore how the participants involved themselves in personcentered lifestyle groups after stroke in Norway.	Randomized controlled trial / qualitative study	IV: Sharing similar experiences DV: Improved post-stroke perceptions	Semi- structured interviews	6	The participants in the study were chosen from a sample of participants who took part in the larger study designed as a randomized controlled trial concerning the development, implementation and evaluation of lifestyle groups.	Four men and two women agreed to be interviewed, and resulted in two participants from three senior welfare centers. The participants' Barthel ADL Index measures showed that they were independent in everyday occupations such as hygiene, eating and mobility. The participants' Mini Mental State Examination scores, showed that the participants had good cognitive capacity.	The participants were active contributors in the groups and pushed each other and themselves regarding involvement in meaningful occupations. This active participation seemed to bring the participants' resources into focus and contrasted with the frequent negative perceptions of people post-stroke as 'victims'.

Authors	Year Pub	Article Title	Theory	Journal	Purpose and take home message	Design/ Analysis /Level of Evidence	IV DV or Themes concepts and categories	Instr. Used	Sample Size	Sample method	Subject Charac.	Comments/critique of the article/methods GAPS
Sullivan, Omonyele, Engle, Shin, Afable, Rudin et al.	2018	Identifying and overcoming implementation challenges: Experience of 59 noninstitutional long-term services and support pilot programs in the Veterans Health Administration	Transformation Model	Health Care Management Review	This study sought to identify the challenges LTSS programs experienced over the course of a large-scale evaluation and describe strategies sites used to overcome these challenges. Anticipating potential pitfalls of program implementation for future noninstitutional LTSS programs can improve implementation efficiency and program sustainability.	Semistructured qualitative interviews	Organizational	interview guide featuring questions about the structure of the pro-gram, implementation progress, and organizational practices	217	process evaluation of LTSS program implementa tion at 59 sites	aging Veterans that seek care from the Departme nt of Veterans Affairs	This study highlights several common challenges programs can address during the program implementation. The most often mentioned strategy was effective communication. Strategies also targeted several components of the organization including organizational functions and processes (e.g., importance of coordination within a team and across disciplines to provide good care), information technology and human resources), and program fit with priorities in the organization (e.g., leadership support).
Gabbe, Reno, Clutter, Schottke, Price, Calhoun, Sager, & Lynch	2017	Improving Maternal and Infant Child Health Outcomes with Community- Based Pregnancy Support Groups: Outcomes from Moms2B Ohio	Life course model	Maternal and Child Health Journal	To describe temporal changes in maternal and child health outcomes in an impoverished urban community after the implementation of a community-based pregnancy support program. Implementation of an innovative community-based pregnancy support program was associated with important improvements in maternal and infant health in an impoverished neighborhood.	Program evaluation	IV: Maternal and child health outcomes DV: Increased support	The Edinburgh Post-natal Depression Scale, the Medical Outcomes Study Social Support Survey, the Perceived Stress Scale, the Adverse Childhood Experiences, the Food Security Scale- Short Form, the Women, Infants, and Children Infant Feeding Practices Study Breastfeeding Scale, the Prenatal Psychosocial Profile Hassles Scale, and other instruments designed or adapted by the research team to measure housing instability, intimate partner violence, and nutrition self- efficacy.	195	Women who attended one or more Moms2B sessions	75% were African- American with incomes below \$800 per month and significant medical and social stressors	Program for pregnant women focused on improving nutrition along with increasing social and medical support that resulted in immediate measurable improvements in maternal and infant health outcomes.

Authors	Year Pub	Article Title	Theory	Journal	Purpose and take home message	Design/ Analysis /Level of Evidence	IV DV or Themes concepts and categories	Instr. Used	Sample Size	Sample method	Subject Charac.	Comments/critique of the article/methods GAPS
Watson, Lambert, & Machin	2016	Peer support training: Values, achievements and reflections	peer support module	Mental Health Practice	This article describes the Institute of Mental Health's training team's values, achievements and reflections accumulated over five years of learning.	Quality improvement, program evaluation	IV: Peer support DV: Increased knowledge base	Interviews	Not reported	Not reported	Members and instructors of mental health support groups	The benefits range from economic advantages, such as a decrease in admissions and relapse rates, to emotional benefits, such as increased feelings of empowerment and hope. In parallel with these benefits, individuals employed as peer support workers can feel more empowered in their own recovery journey, more confident, and more positive about their identity. They are also less likely to self-stigmatize, they have more skills, more money and feel more valued. Peer support is generally seen as a positive, safe way to reenter the job market and resume an important social role.
Zavoda	2015	The Evolution of a Low Vision Support Group	Peer support training	OT Practice	The purpose is to describe the process and evaluation of a support group. Lessons learned include the subtleties and intuition of how to facilitate a support group, as well as the importance of not trying to control the group process.		IV: Social support. DV: Improved well-being	Not reported	15	Members from the Low Vision Support Group	Not reported	It is helpful to develop a tradition and to set expectations within the group. A flexible agenda can be useful, as long as it allows for the group process to occur naturally. Use of keen observational skills and the artful nuances of knowing when to facilitate the discussion, re-direct the group to another topic, and maintain sensitivity to each individual's comfort level in the group are all key skills. It is important to observe the body language of the members, to ascertain if anyone is withdrawn, frustrated, or emotional.
Evans, et al.	2020	The impact of the implementation of the Dutch combined Meeting Centers Support Programmed for family caregivers of people with dementia in Italy, Poland and UK	Improved caregiver support leads to better patient outcomes	Aging & Mental Health	The project aimed to implement the combined Dutch Meeting Centre Support Program for community-dwelling people with dementia and caregivers within Italy, Poland and UK and to assess whether comparable benefits were found in these countries as in the Netherlands.	Level III	IV: Support and education DV: Increased satisfaction	7-item Short Sense of Competence Questionnaire	598	The target group were people with mild to moderate dementia and their family caregivers attending meeting centers.	people with mild to moderate dementia and their family caregivers	The moderate positive effect on sense of competence and the greater mental health benefit for lonely caregivers using the Meeting Centre Support Program compared to usual care as found in the original Dutch studies were not replicated. However, subject to study limitations, caregivers in Italy using Meeting Centre Support Program benefitted more regarding their mental health and emotional distress than caregivers using usual care.

Authors	Yar Pub	Article Title	Theory	Journal	Purpose and take home message	Design/ Analysis /Level of Evidence	IV DV or Themes concepts and categories	Instr. Used	Sample Size	Sample method	Subject Charac.	Comments/critique of the article/methods GAPS
Malini	2015	Impact of support group intervention on family system strengths of rural caregivers of stroke patients in India	Support group interventions improve the strength of family systems	The Australian Journal of Rural Health	The objective of this study was to evaluate the impact of support group intervention on family system strengths of rural caregivers of stroke patients.	Level III. Experimental pretest and post-test design	IV: Support group intervention DV: Family system strength	Family System Strengths questionnaire for both the groups. Descriptive and inferential statistics were used to analyze the data.	A total of240 participants, 120 were in the experimental group and 120 in the control group	simple random sampling technique	Caregivers of patients with stroke for more than 1 year, unemployed caregivers, female caregivers, caregivers willing to participate in the study and caregivers who were able to understand the local language, Tamil.	There was a significant and positive increase in the family system strengths of caregivers who participated in the self-help group meetings, thereby suggesting that support group intervention programs are an effective nursing strategy that can be employed for improving the overall well-being of the caregivers of stroke patients.
White	2016	Optimizing social outcomes through stroke support groups	Social outcomes and Subjective Index of Physical and Social Outcomes	American Nurse Today	This study demonstrated that stroke support groups were related to the stroke survivor's resocialization outcomes. This suggests that stroke support groups can positively impact social functioning and reintegration into the community after a stroke. The potential of stroke support groups should be further studied for their impact on overall social functioning and quality of life in stroke survivors.	non- experimental cross- sectional design	IV:	a researcher developed demographic survey and the Subjective Index of Physical and Social Outcomes [SIPSO] tool	105	At the end of the 30-day return period nonparametric statistics were used to evaluate the hypotheses that stroke survivors who attend a stroke support group will reenter into community interaction/ socialization sooner that those stroke survivors that do not attend a stroke support group.		Participants who attended stroke support groups had significantly better resocialization.

Authors	Year Pub	Article Title	Theory	Journal	Purpose and take home message	Design/ Analysis /Level of Evidence	IV DV or Themes concepts and categories	Instr. Used	Sample Size	Sample method	Subject Charac.	Comments/critique of the article/methods GAPS
Deering, Fieldhouse, & Parmenter	2016	What helps successful community groups (involving peers support workers) to develop?	Support groups can improve the well-being of its participants	Mental Health and Social Inclusion	The purpose of this paper is to explore features of successful peer supported community support groups. Overall the review confirmed existing findings that successful support groups foster mutually supportive, reciprocal relationships capable of inspiring hope among group members.	Literature review and theme construction						A group's success was seen in terms of growth in members' self-esteem, empowerment, and optimism, which this paper proposes could become part of a conceptual framework of a learning organizational culture. Developing understanding of a rapidly growing phenomenon in community-based mental health care and presenting this in terms of a particular organizational culture.
Boger, Demain & Latter	2015	Stroke self- management: A focus group study to identify the factors influencing self- management following stroke	Perspectives that facilitate or hinder self- management	International Journal of Nursing Studies	Successful stroke self-management consists of features which may be modifiable at the individual level, in addition to the presence of external support and an environment which supports and facilitates people following stroke to self-manage. These findings extend current conceptualizations of stroke self-management.	Qualitative, Five focus groups	IV: self management environment DV: Individual capacity; support for self- management	semi- structured interview	28	Participants had experienced a stroke	rural and urban community stroke support groups based in the South of England	The term 'self-management' was unfamiliar to participants. Self-management was viewed as an important, unavoidable feature of life after stroke. People following stroke reported feeling ill-prepared to self-manage. The self-management support needs of patients following stroke are currently often unmet.

# Appendix B

# **Support Group Session Evaluation Tool**

	YOUR OF	PINION COUNTS!
· -	g purposes. All respo y.	I in knowing what you think. Your feedback will be nses are completely anonymous. Thank you for taking
1) What is your age?	3)	How would you describe yourself?
Under 18 years old	18-24 years old	American Indian or Alaska Native
25-34 years old	35-44 years old	Asian
45-54 years old	55-64 years old	Black or African American
65-74 years old	75-84 years old	Native Hawaiian or other Pacific Islander
Over 84 years old		White
2) Gender?		Hispanic, Latino, or of Spanish origin

# Appendix C

# **Program Planning Team Evaluation Tool**

	YOUR OPINION COUNTS
mporta	gram committee members are interested in knowing what you think. Your feedback will be not for future planning purposes. All responses are completely anonymous. Thank you for taking complete this survey.
Date:	
I) Occu	pation?
2) Cred	entials:
3) Years	s of experience:
1) Did y	ou attend the session? Yes No
5) Is the	meeting schedule adequate? Yes No
6) Is the	space adequate for the session? Yes No
7) Were	the objectives of the support group met? Yes No
3) Woul	d you be willing to participate in activities planned outside of meetings? Yes No
9) Are y	ou willing to be a speaker? Yes No
10) Do <u>y</u>	you have any recommendations on future topics? Yes No
I1) Wha	at changes would you recommend for the next meeting?

## Appendix D

## **Support Group Session Guidelines**

We are so excited to be offering Support Programs virtually! Thank you for being willing to participate in this group, and for having the courage to practice something that may be out of your comfort zone. Please see below for more meeting details:

We will be holding our group on WebEx, and meeting details are listed below. We encourage you to sign on early if you need time to familiarize yourself with the WebEx platform. You are welcome to call in to the meeting using the provided phone numbers if you'd prefer phone instead of the computer. This may be somewhat new for many of us.

#### Please read over our group guidelines before joining in:

- Find a location in your home that provides privacy and limited distractions
- Keep everything shared here confidential. We want it to be a safe, secure place for all to talk.
- Give everyone who wants to share a chance to talk.
- Share information one at a time (it helps to mute your volume while someone else is speaking)
- We try to accept people, just as they are, and we avoid making judgements
- Do not force anyone to share more than they want to.
- If you want to share a thought with somebody about their story, ask if they want feedback or input before giving it.
- We share our own feelings and experiences; we do not give medical advice

If you have any questions, feel free to send an email to greensboro@joeniekrofoundation.org.

#### YOUR OPINION COUNTS!

The program committee members are interested in knowing what you think. Your feedback will be important for future planning purposes. All responses are completely anonymous. Thank you for taking time to complete this survey.

Survey Link https://s.surveyplanet.com/WKqiv8bay

Next Meeting is on November 19<sup>th</sup> at 6:30 pm via WebEx. The same meeting link that you used to join tonight's meeting, will also be the link for all future sessions.

## Appendix E

## **Support Group Session Agenda**

#### **Meeting Agenda**

Location: WebEx

September 17th, 2020 6:00 PM - 7:00 PM

Host:

Speaker:

Time Topic

6:00 PM - 6:10 PM Meet and Greet

6:10 PM – 6:20 PM Welcome and speaker introduction

6:20 PM – 6:50 PM Speaker – Current State of Stroke Diagnosis and Treatment

6:50 PM – 7:00 PM Open Discussion and Session Evaluation Discussion

## \*\*\* REMINDERS AND NOTICES \*\*\*

- Upcoming Speaker
  - •
  - How to navigate holiday eating
- Our next support group meeting is October 15<sup>th</sup> from 6:00 PM 7:00 PM

The purpose of our support group is to help everyone realize that they are not alone. We believe that this goal may be achieved by offering everyone the opportunity to share their experiences, and resources with others in the group.

## THANK YOU FOR COMING!

## Appendix F

## **Support Group Flyer**



# BRAIN ANEURYSM, AVM & HEMORRHAGIC STROKE SUPPORT GROUP

WHERE:

Webex Video Meeting

WHEN:

Every Third Thursday of the month

TIME:

6:30pm-7:30pm

## **INFORMATION:**



greensboro@joeniekrofoundation.org

Search Greensboro Brain Aneurysm,

f

AVM & Hemorrhagic Stroke Support Group

The purpose of this support group is to provide survivors and their caregivers an opportunity to support each other as they strive to rebuild their lives and promote health, independence and well-being.







Appendix G

## **Project Implementation Timeline**



# Appendix H

# **Support Group Budget**

Item	Description	Quantity	Cost	Total
Online meeting site	WebEx	3 months	\$13.50	\$40.50
Direct Mail	Paper & Printing	100	\$0.15	\$15.00
Direct Mail	Postage	100	\$0.55	\$55.00
Direct Mail	Envelopes	100	\$0.10	\$10.00
Support Group informational flyers	Paper & Printing	250	\$0.15	\$37.50
Total			•	\$158.00

## Appendix I

## **Support Group Announcement Letter**



November 5, 2020

We are excited to share that Cone Health has teamed up with the Joe Niekro Foundation to found a Support Group for patients and family members affected by a brain aneurysm, AVM or hemorrhagic stroke. The group will be meeting monthly to come together to share stories, offer helpful resources and assist with ongoing support for survivors and their families.

The Joe Niekro Foundation (JNF) was established in 2007. Joe Niekro was a twenty-two year veteran of professional baseball who suddenly lost his life from a cerebral brain aneurysm in October 2006. The astonishing lack of public awareness and under-support of research led to the launch of a crusade to educate and encourage awareness about brain aneurysms and other cerebral disorders.

The Greensboro Chapter of the JNF support group will meet monthly via WebEx. We encourage all patients, family members and caregivers to join us. Our goal for the group is to help bridge the gap, encourage collaboration and to facilitate a comprehensive support program for survivors and their families.

If you or someone you know would like to attend the support group meeting please contact:  $\underline{ greensboro@joeniekrofoundation.org}$ 

Join our group Facebook page: https://www.facebook.com/groups/1474418246071221

Support group sessions occur on the third Thursday of every month.

Meeting Time: 6:30 pm - 7:30 pm

Dates: 11/19/2020 12/17/2020 1/21/2021 2/18/2021 3/18/2021 4/15/2021

Sincerely,

# Appendix J

# **Doctor of Nursing Practice Essentials**

	Description	Demonstration of Knowledge
Essential I  Scientific Underpinning for Practice	Competency – Analyzes and uses information to develop practice  Competency -Integrates knowledge from humanities and science into context of nursing  Competency -Translates research to improve practice  Competency -Integrates research, theory, and practice to develop new approaches toward improved practice and outcomes	The project was developed using research from multiple different fields. The research was taken and developed into an evidenced-based plan to create and implement a support group.  Throughout the project's development, new approaches to successfully delivering a support group were a must due to the pandemic.  Working towards developing best practices for online support groups was a significant accomplishment and helped move healthcare delivery forward.
Essential II  Organizational & Systems Leadership for Quality Improvement & Systems Thinking	Competency –Develops and evaluates practice based on science and integrates policy and humanities  Competency –Assumes and ensures accountability for quality care and patient safety  Competency -Demonstrates critical and reflective thinking  Competency -Advocates for improved quality, access, and cost of health care; monitors costs and budgets  Competency -Develops and implements innovations incorporating principles of change  Competency - Effectively communicates practice knowledge in writing and orally to improve quality  Competency - Develops and evaluates strategies to manage ethical dilemmas in patient care and within health care delivery systems	<ul> <li>This project helped to develop a form of healthcare delivery for the community that was not previously available.</li> <li>Creating an online support group opens up more ways for community members to seek the support they need.</li> <li>It helped to remove potential barriers and aimed to decrease the overall cost and utilization of healthcare resources.</li> <li>Improving the outcome of just one person could lead to a substantial cost and resource-saving within the community.</li> <li>Accountability of the interventions was ensured by creating a multidisciplinary team that created and discussed all aspects of the project.</li> </ul>
Essential III	Competency - Critically analyzes literature to determine best practices	When creating the project plan, multiple databases
Clinical Scholarship & Analytical Methods for Evidence-Based Practice	Competency - Implements evaluation processes to measure process and patient outcomes  Competency - Designs and implements quality improvement strategies to promote safety, efficiency, and equitable quality care for patients  Competency - Applies knowledge to develop practice guidelines  Competency - Uses informatics to identify, analyze, and predict best practice and patient outcomes  Competency - Collaborate in research and disseminate findings	were accessed to obtain the highest quality of data available.  • The data was then critically analyzed by using Melnyk Levels of Evidence and synthesized into a plan to create and implement a support group to provide its participants with the highest quality support group possible.  • Evaluation tools were created to help evaluate the process and ensure project outcomes were being met.  • The RE-AIM framework and PDSA cycles were used to help implement changes and track the outcomes of changes made.

	Description	Demonstration of Knowledge
Essential IV  Information Systems – Technology & Patient Care Technology for the Improvement & Transformation of Health Care	Competency - Design/select and utilize software to analyze practice and consumer information systems that can improve the delivery & quality of care  Competency - Analyze and operationalize patient care technologies  Competency - Evaluate technology regarding ethics, efficiency and accuracy  Competency - Evaluates systems of care using health information technologies	The program planning team evaluated multiple online meeting platforms to use in the delivery of the support group.  Out of all the trialed platforms, WebEx was chosen as the best to deliver the support group.  The IT department was consulted for assistance with obtaining participant contact information and group contact information.  The electronic medical record system was evaluated to disseminate the support group's information to potential participants.
Essential V  Health Care Policy of Advocacy in Health Care	Competency- Analyzes health policy from the perspective of patients, nursing and other stakeholders  Competency – Provides leadership in developing and implementing health policy  Competency – Influences policymakers, formally and informally, in local and global settings  Competency – Educates stakeholders regarding policy  Competency – Advocates for nursing within the policy arena  Competency - Participates in policy agendas that assist with finance, regulation and health care delivery  Competency – Advocates for equitable and ethical health care	The project supported the goals of the acute care facility by helping it fulfil its mission and requirements associated with being a Comprehensive Stroke Center.     The creation of this project helps to aid the community and local healthcare facilities achieve the goals related to stroke as set by Healthy People 2020.     One of the key founding principles of the support group was to eliminate financial and physical barriers that could exclude parts of the community.
Essential VI  Interprofessional Collaboration for Improving Patient & Population Health Outcomes	Competency- Uses effective collaboration and communication to develop and implement practice, policy, standards of care, and scholarship  Competency – Provide leadership to interprofessional care teams  Competency – Consult intraprofessionally and interprofessionally to develop systems of care in complex settings	<ul> <li>The project addressed many different aspects of health that are typically delivered through many different disciplines.</li> <li>To ensure the project was providing accurate and relevant content, a multidisciplinary team was created to manage the support group.</li> <li>All decisions made for the group came from a collaborative effort of the program planning team.</li> <li>The DNP student assumed the project leader's role and co-leader of the planning team.</li> <li>Additional members of the program planning team consisted of physical therapists, occupational therapists, stroke program manager, and a neurosurgeon.</li> <li>During the planning phase, the project lead collaborated and consulted with key stakeholders that included the stroke program manager, neurosurgeons, the head of the neurology department, neurologists, neurointensivist, advanced practice nurses, physician assistant, and a neurology clinical nurse specialist.</li> <li>To help create the support group, departments that were collaborated with included IT, philanthropy, medical records, digital communication, privacy, community education, and facilitators of other support groups.</li> </ul>

	Description	Demonstration of Knowledge
Essential VII Clinical Prevention & Population Health for Improving the Nation's Health	Competency- Integrates epidemiology, biostatistics, and data to facilitate individual and population health care delivery  Competency – Synthesizes information & cultural competency to develop & use health promotion/disease prevention strategies to address gaps in care  Competency – Evaluates and implements change strategies of models of health care delivery to improve quality and address diversity	A gap in support for hemorrhagic stroke patients was identified and addressed.     Through analyzing and synthesizing the research, plans for a new support group was developed and implemented.     Through the continual evaluation of the support group and its outcomes, the group will continue to function as a resource for participants to receive high-quality care developed specifically for their needs.
Essential VIII Advanced Nursing Practice	Competency- Melds diversity & cultural sensitivity to conduct systematic assessment of health parameters in varied settings  Competency – Design, implement & evaluate nursing interventions to promote quality  Competency – Develop & maintain patient relationships  Competency – Demonstrate advanced clinical judgment and systematic thoughts to improve patient outcomes  Competency – Mentor and support fellow nurses  Competency – Provide support for individuals and systems experiencing change and transitions  Competency – Use systems analysis to evaluate practice efficiency, care delivery, fiscal responsibility, ethical responsibility, and quality outcomes measures	During the planning and implementation phase, the diversity of the potential participants played a key role in the decisions made.     The original meeting location was chosen to be easily accessible to everyone regardless of disability or socioeconomic status.     This support group allows nursing to have additional avenues to interact with community members and deliver health education.     The many opportunities for participation can offer an excellent way for new nurses to give back and learn from more experienced individuals.