

**Why are African-Americans with Dysphagia Post-Stroke Having Higher Rates of PEG
Placement?**

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Abstract

Throughout the history of this country, systemic issues have trickled into certain communities impacting them severely. Whether this be with environmental threats, poverty, inadequate access to quality health care, educational inequality, or lack of employment opportunities. All these problems have been deeply programmed into society and our institutions. They have been beneficial for some groups, but detrimental for others. One group of people who have been harmed by these systemic inequalities, are African Americans. This thesis will explore these disparities as it relates to African-American stroke survivors with dysphagia, specifically the higher occurrences of percutaneous endoscopic gastronomy tube (PEG) placement in this community. With a review of various literature, four factors were examined as possible contributing variables: residential segregation, insurance, implicit bias, and severity of stroke.

Keywords: communication disorders, African Americans, stroke, dysphagia, post-stroke, PEG tube, percutaneous endoscopic gastronomy tube, systemic issues, systemic inequality, healthcare

According to the Centers for Disease Control and Prevention, every 40 seconds, someone in the U.S. suffers a cerebrovascular accident, also known as a stroke. Every 3.5 minutes, someone dies due to one. The risk of suffering a stroke is widely varied depending on race and ethnicity. The risk of having a stroke is nearly twice as high for African-Americans than it is for Whites and they also have the highest rate of death due to stroke (Centers for Disease Control and Prevention [CDC], n.d.). Even for those individuals who survive a stroke, there is a possibility that there will be lasting health effects. These can include paralysis, visual impairments, aphasia, memory problems, and issues with swallowing, known as dysphagia (John Hopkins Medicine, n.d.). With there being so many possible outcomes from a stroke, the care after one is very vital in ensuring someone's progressive recovery. This is not always achieved due to the huge disparities in our country's healthcare system. These disparities arise because of systemic problems that have been deeply rooted into society and our institutions. All these problems are interdependent and interconnected. This includes environmental threats, poverty, inadequate access to quality health care, educational inequality, and lack of employment opportunities (CDC). These disproportional gaps are very common when it relates to the African-American community and it is evident in post-stroke care. Literature has indicated that African-Americans with dysphagia post-stroke have higher rates of PEG placement. Why is this happening? Are there patterns and connections at play? The purpose of this thesis is to explore the mediating variables for this occurrence through a review and analysis of literature.

Strokes

To fully comprehend what is going on, it is important to firstly address all-encompassing topics. In this case, it must begin with understanding what a stroke is. A stroke is known as a brain attack because there are parts of the brain that either die or are damaged (American Stroke

Association [ASA], n.d.) Whenever something happens to disrupt our brain, it can lead to very life-threatening events because of how many functions our brain is responsible for. The brain has control over our movements, vision, memories, emotions, and breathing, just to name a few (JHM, n.d.). So, when someone has a stroke, it can affect their physiology badly.

There are two main kinds of stroke: ischemic and hemorrhagic. Ischemic stroke happens when there is a blood clot or plaque that blocks off the flow of blood to the brain (ASA, n.d.). This is detrimental because our brain needs oxygen, and it is through the blood flow that we receive it; without it our brain cells begin to die (ASA, n.d.). The hemorrhagic stroke occurs when there is a blood vessel that ruptures in the brain (ASA, n.d.). The blood accumulates and adds a significant amount of pressure on the neighboring brain tissue, damaging the brain (ASA, n.d.). This can also lead to brain cells dying because the compression increase on the brain may reduce the needed blood flow.

Stroke in the African-American Community

Strokes are ranked as the fifth leading cause of death and disability in the United States and as mentioned in the introduction, many of those afflicted by stroke are people in the African American community (CDC, n.d.). Many African Americans also have at least one of the risk factors associated with stroke such as diabetes, high cholesterol, high blood pressure, and sickle cell anemia (ASA, n.d.). Aside from having a higher incidence of stroke, African American stroke survivors compared to other racial groups are more likely to be disabled and struggle with doing daily activities independently.

Effects of stroke

When someone experiences a stroke there are a wide range of potential effects dependent on the “type, severity, and location,” (JHM, n.d.). Whether it is an ischemic or hemorrhagic

stroke, and how severe the stroke was plays a role in the effects people experience, but the location of the stroke is also another factor. As mentioned previously, the brain has various functions and specific regions of the brain are what allow them to play out. There are three main parts of the brain. The cerebellum, known as the “little brain,” is in the back of the brain (National Institute of Neurological Disorders and Stroke [NINDS], n.d.). The cerebrum which is split up into the right and left hemispheres (NINDS, n.d.). Then there is the brainstem, which serves as the connection between the brain and spinal cord and is also the site of life-supporting functions (NINDS, n.d.). After a stroke, if there is damage to the cerebellum, this can cause someone to experience issues with balance and coordination, nausea, and dizziness (JHM, n.d.). If there is a stroke in the left hemisphere of the cerebrum, it can lead to right side paralysis, issues with speech and understanding language known as aphasia, and depression (JHM, n.d.). If the stroke is in the right hemisphere, it is possible that the victim will have memory problems, visual impairments, or left side weakness (JHM, n.d.). A stroke in the brainstem can potentially lead to issues with heart and breathing functions, coma, or difficulties swallowing known as dysphagia (JHM, n.d.).

Dysphagia

Dysphagia is described by the American Speech-Language-Hearing Association as “a swallowing disorder involving the oral cavity, pharynx, esophagus, or gastroesophageal junction.” When someone has dysphagia, this can lead to compromised health. They can suffer from malnutrition and dehydration, choking, painful swallowing, chronic cough, lung disease, and aspiration pneumonia (ASHA, n.d.) Dysphagia can even be deadly. A person with dysphagia can also deal with social issues such as reduced interest, lack of enjoyment, self-consciousness, or isolation especially in spaces that involve eating or drinking (ASHA, n.d.). Living with dysphagia may demand changes to one’s lifestyle and those around them along with “increased caregiver costs and burdens,” (ASHA, n.d.). As mentioned above, brain stem strokes impair swallowing physiology. According to Martino and colleagues (2005), brain stem strokes result in the largest swallowing compromise. These brain stem lesions impact the sensation of the mouth in the tongue and cheek areas, the timing of the pharyngeal swallow, the elevation of the larynx, and closing of the glottis (Martino et al., 2005). In regard to incidence, a study by Falsetti and colleagues (2009) discovered that of all the patients admitted into stroke rehabilitation units, over

one third of them had dysphagia. It has also been suggested that 50% of stroke survivors are affected by dysphagia (González-Fernández, 2013). Most of the time it is common for adults over the age of 50 to have dysphagia after a stroke (ASHA, n.d.).

Dysphagia Treatments

There are a wide array of treatments and interventions that can be carried out to assist someone with dysphagia. For instance, there is swallowing therapy which is led by a speech-language pathologist. This could consist of swallowing exercises, compensatory swallowing strategies, diet modifications, and educating the patient/caregiver (ASHA, n.d.). This is done so that there can be improvements in the patient's swallowing function (ASHA, n.d.). Diet modifications can include changes to the consistency of liquids and foods they consume (Garcia et al., 2010). Someone with dysphagia can also be taught certain maneuvers that alter the strength and timing of certain movements while swallowing (ASHA, n.d.). It is fair to mention that most of these maneuvers are best to be taught to patients without cognitive impairments, as they require multiple steps (ASHA, n.d.) An example of a maneuver is effortful swallow, in which the patient adds more pressure to their mouth and tongue, as well as their upper pharynx (ASHA, n.d.). This also helps with drawing back the tongue's base (ASHA, n.d.). The swallowing exercises involve the jaw, lips, soft palate, tongue, larynx, pharynx, as well as respiratory muscles (ASHA, n.d.). They help to strengthen the swallowing muscles (ASHA, n.d.). This means there may be chewing and resistance exercises as well as range-of-motion activities (ASHA, n.d.). Specific exercise examples are laryngeal elevation exercises, which involve lifting and maintaining the larynx in an elevated position (ASHA, n.d.). There are also postural techniques which fall under the compensatory swallowing strategies. This technique redirects the movement of the bolus in the oral cavity and pharynx and alters the pharyngeal dimensions. An example of a postural technique is known as the chin-down posture which is

when the chin touches the neck during swallowing which makes the opening to the airway narrow, therefore preventing choking (ASHA, n.d.).

Aside from these therapies, feeding tubes are also used to treat dysphagia. These are devices used for the nutrition of individuals who have issues with their swallowing functions. There are a variety of feeding tubes. The jejunostomy tube, also known as a PEJ or J-tube, is put through the abdomen and into the second part of the small intestine, jejunum (ASHA, n.d.). There is the nasogastric tube, also known as the NG-tube, which is put through the patient's nose into the esophagus and then the stomach. This is usually a tube intended for short term use (ASHA, n.d.). Then there are gastrostomy tubes. The percutaneous endoscopic gastrostomy tube, also known as PEG tube, is the most used (ASHA, n.d.). This tube is of particular interest because of its connection to the African-American community.

PEG Tubes

In 1980, the percutaneous endoscopic gastrostomy [PEG] tube was created by Jeffrey Ponsky and Michael Gauderer (Strong & Ponsky, 2017). This was a huge innovation in the practice of gastroenterology because it was an alternative to open surgical gastrostomy that was effective (Plonk, 2005). Not only did it provide nutrition for the patient, but it also was more cost efficient. The PEG tube is used for long-term feeding, and it is recommended for patients if they do not have the needed physiological functions to engage in safe swallowing even after there has been alterations to food and liquid consistencies or compensatory strategies (American Society for Gastrointestinal Endoscopy [ASGE], n.d.). The PEG tube makes it possible for nutrients, liquids, and medications to go to the stomach (ASGE, n.d.). The food is in the form of enteral formulas, which are food products in liquid form (ASGE, n.d.). The process of PEG placement usually only requires local anesthesia, antibiotics, and an IV sedative (ASGE, n.d.). A surgeon is

able to complete the procedure with the use of an endoscope, a flexible tube to create a small opening through the skin of the upper abdomen and into the stomach (ASGE, n.d.). A PEG tube is used for a wide array of conditions such as cerebral palsy, traumatic brain injuries, dementia, and strokes (Rahnemai-Azar et al., 2014). Ultimately, a PEG tube is the option that allows for humans to get nutrition who would not have survived without it; especially for someone with dysphagia who is in danger when drinking or eating and could experience aspiration. It makes sense that this is such a common procedure, especially because as humans eating is one of our basic needs to survive; without nutrition, we die.

It seems almost simple to make the decision of whether someone does or does not receive a PEG tube, especially if it saves someone from suffering from malnutrition. However, there are risks and complications that arise from PEG tubes. For instance, it can increase the risk of aspiration pneumonia, which is the leading cause of death from a PEG tube (Plonk, 2005). It is also possible that someone bleeds from their PEG tract or that their intra-abdominal organs are injured (Rahnemai-Azar et al., 2014). The person can also get a tube-site infection (Rahnemai-Azar et al., 2014). The PEG tube can either get clogged, dislodged, cracked, or leak (Rahnemai-Azar et al., 2014). Some people with PEG tubes complain of discomfort (Coyle & Leslie, 2010). They may also have excessive bowel movements or lack thereof (Plonk, 2005). In a 2017 study, using a community-based sample, out of 174 patients post-stroke 54% died 6 months after PEG placement complications (Meisel et al., 2017).

African-Americans and High Rates of PEG Placement

In a 2005 study about the advantages and disadvantages of PEG tubes, it was stated that “other studies showed particularly...marked racial disparities with blacks receiving tubes at nearly twice the rate of whites,” (Plonk, 2005). This was mentioned in passing and there was not

any elaboration on the possible factors behind this difference, which led to further inquiry. The study Plonk referenced in that quote was published in 1998 and focused on looking at gastrostomy placement among Medicare beneficiaries that were hospitalized (Grant et al., 1998). It was important to determine whether this was still happening in recent years. A study from January 2022 found that Black patients still had higher odds of receiving a PEG tube versus White patients (Henaio et al., 2022). Another study from 2016 suggested there were certain risk factors or predictors for receiving a PEG tube. The predictors included age, Glasgow Coma Scale, intracerebral hemorrhage volume, and being African-American (Faigle et al., 2016). Ultimately, they were saying that an individual can possibly end up with a PEG tube if they fall under the array of quantitative variables, or if they fall under a categorical variable, like race. Like the first study mentioned, the authors were not entirely clear on why this was the case, but it was imperative to dive deeper into this. This brought up possible links to the systemic and structural system within the United States and how it can be unjust for certain groups of people. Could this be the reason as to why African Americans with dysphagia post-stroke had higher rates of PEG placement?

Contributing Variables

Across various studies, there were four common explanatory factors that could possibly be contributing to the disparities in PEG placement: residential segregation, insurance, implicit bias, and stroke severity. Residential segregation is the “physical separation of the races by enforced residence in certain areas... an institutional mechanism of racism that was designed to protect whites from social interaction with blacks,” (Williams & Collins, 2001). Residential segregation originated in the 1930s with the use of redlining (Williams & Collins, 2001). Government maps outlined areas where Black residents lived, and these areas were deemed risky

investments. Many black people continue to face the aftereffects of this practice. It is sometimes even referred to as a fundamental cause of racial disparities in health (Williams & Collins, 2001). Where individuals reside impact many aspects of their lives.

Wealth Gaps. Economically, for instance, there may a significant difference in wealth between a predominantly Black neighborhood and White neighborhood, referred to as a wealth gap (Quick & Kahlenberg, 2019). This means that many Black neighborhoods tend to be high-poverty and poorly resourced (Quick & Kahlenberg, 2019). This could lead to problems regarding upward mobility due to a lack of employment options. This further affects property taxes. Neighborhoods are able to flourish with the help of property taxes; but if less money is going into property taxes, then less money is being allocated into places such as schools, parks, libraries, and hospitals (Arkin et al., 2022). This presents an issue because when someone is admitted into a hospital in an urban low-income neighborhood, it is more than likely that this hospital will reflect “a lack of resources, specific protocols, or quality/quantity of staff,” (Faigle & Cooper, 2019). For example, a study regarding racial disparities in stroke care mentioned that “minorities use emergency medical services systems less, are often delayed in arriving at the emergency department, and have longer waiting times in the emergency department,” (Cruz-Flores et al., 2011). There has also been research done on some minority-serving hospitals and how those stroke patients have a higher probability of PEG placement compared to those patients in majority white-serving hospitals (Faigle et al., 2019). In this same study, the authors mentioned that these hospitals differ in their “organizational structure, availability of equipment and specialists, and funding,” which sometimes results in worse health outcomes for Black patients in the minority-serving hospitals (Faigle et al., 2019).

Insurance. These issues with income also affect the extent to which insurance is beneficial. If one's income is low, it impacts their ability to cover medical expenses. There are insurance programs such as Medicare and Medicaid that assist in that, but they do not cover all expenses completely. Medicare is a health insurance meant to be used by Americans when they turn 65 or have received social security benefits over a span of 24 months (Medicare, n.d.). Medicaid is a state and federal insurance program intended to assist low-income individuals (Medicaid, n.d.). A PEG, as mentioned previously, is described as "cost efficient," because both Medicare and Medicaid fully cover PEG tube placement (ASHA, n.d.). Their guidelines for allowing PEG placement are "presence of a permanent disorder or condition of the structures that normally permit food to reach the small bowel," which is dysphagia in this case (Newton & Barnabas, 2013). On the other hand, speech therapy services such as swallowing therapy are only 80% covered by these insurances, and the remaining 20% must come out-of-pocket (Medicare, n.d.) A recent study found that the number of Medicaid patients that were PEG tube recipients was significantly higher compared to those not receiving a PEG tube with 15.6% and 8.2% respectively (Faigle et al., 2017). There was also discussion of those same patients living in a "zip code of the lowest quartile of median household income (less than 39,000-41,000 USD per year)," Both Medicare and Medicaid have high percentages of Black beneficiaries (National Committee to Preserve Social Security and Medicare [NCPSSM], n.d.). This is the case because they are likely to "have significantly lower financial resources than White Americans," (NCPSSM, n.d.). This could potentially be a reason as to why many African-Americans are receiving PEG tubes over dysphagia therapy because it is more affordable, but it brings us back to the way things outweigh each other. Dysphagia therapy is more passive in nature and less

intrusive, while PEG tubes can lead to many complications. They are receiving the PEG tubes which are helpful and keep them alive, but at what cost?

Implicit Bias. Another contributing factor to the PEG disparities is implicit bias. According to the National Institutes of Health, implicit bias is “a form of bias that occurs automatically and unintentionally, that nevertheless affects judgments, decisions, and behaviors.” It is very harmful. This is specifically tied to what goes on in hospitals and the preconceived notions that health-care professionals have. This is an issue because it can affect the decision-making process, and that jeopardizes the lives of Black patients (Faigle & Cooper, 2019). For instance, a study found that there was implicit bias in decision-making to treat patients with thrombolysis (Green et al., 2007). Thrombolysis is a treatment that assists in breaking down a blood clot that blocks the flow of blood to the brain. It “improves patient outcomes in stroke,” due to being administered almost immediately after stroke onset, or somewhere within three hours (Meretoja et al., 2014). In the study, a group of 297 physicians took an Implicit Association Test. This is a computer-based test to measure unconscious bias and the way individuals associate attributes to certain groups (Green et al., 2007). The investigators found that many of the physicians had “implicit preference favoring white Americans and implicit stereotypes of black Americans as less cooperative with medical procedures and less cooperative generally,” (Green et al., 2007). This led to the likelihood that white patients would be offered and treated with thrombolysis more often than black patients (Green et al., 2007), meaning black patients had lower rates of thrombolysis (Green et al., 2007). This is daunting information because the more severe a stroke is; the more likely it is for another Black person to end up with dysphagia and a PEG tube. The low rates of thrombolysis contribute to the higher rates of

gastrostomy tubes and other “life-sustaining procedures, such as intubation and tracheostomy,” of Black stroke patients (Faigle & Cooper, 2019).

Stroke severity. The severity of stroke is also a principal factor in the overuse of PEGs among Black patients. According to the CDC, “Time lost is brain lost. Every minute counts.” To prevent severe strokes, timing is everything. The amount of time elapsed between a stroke and getting medical assistance changes outcomes. Yet, lack of funding due to racial segregation means inadequate resources, understaffed hospitals, lack of certain protocols, equipment, and specialists (Cruz-Flores et al., 2011). Black patients experiencing longer waits in the emergency room means they will not get help as quickly and may end up with a severe stroke (Cruz-Flores et al., 2011). Economic instability means they may have the tendency of opting out of calling ambulances, because of how expensive the bill will be (Cruz-Flores et al., 2011). This leads to delayed arrivals to the emergency department and a stroke that is more severe. Unconscious bias means they may not be provided with thrombolysis treatment, which will make matters worse instead of lessening the effects of a stroke (Green et al., 2007). All these factors add up, and with more severe strokes come higher levels of dysphagia and PEG tube placement.

Systemic Inequality

Each of these factors are associated with systemic inequality. Systemic inequality is an overarching term that can take on many forms. As described by Arkin and colleagues (2022) it is “pervasively and deeply embedded in systems, laws, written or unwritten policies, and entrenched practices and beliefs that produce, condone, and perpetuate widespread unfair treatment and oppression of people of color, with adverse health consequences.” In the grand scheme of things, systemic issues trickle down into the reasons there are higher rates of PEG placement African-Americans with dysphagia post-stroke. These systemic problems call for

systemic changes, because they are ingrained into our institutions and society. There would need to be more law and policy reform. Current and future health-care professionals might need to receive better training on unlearning implicit biases. More employment opportunities meaning there will be social mobility, influx of income, and more funding from property taxes.

There should also be more conversations and reflections on not only equality, but equity. These require more collective efforts than individual ones, but I also thought it would be beneficial to find individual approaches.

Outreach & Future Studies.

Severity of stroke was a factor that could potentially be lessened. I went back into my neighborhood of East New York, Brooklyn, a predominantly Black neighborhood, to do outreach. I visited a senior citizen center where I gave a presentation on strokes and how to detect when one was happening. This is especially important because, as mentioned before, severity of stroke depends on how quickly someone receives medical attention. Many of the times, people are not even aware of the signs and symptoms leading up to a stroke and if that is taught, they can take that knowledge and apply it if ever presented with a situation that requires it. If help is immediately sought this prevents more brain cells from dying and less severe strokes. I also gave some pointers on how to lessen the chances of stroke such as changing diets, being more physically active, and managing pre-existing conditions. This is crucial because they should be taking care of themselves just as much as they would their neighbor. Doing this will not necessarily solve the entire problem, but when people in the very community that are impacted by these disparities are educated on these topics it will decrease the markers linked with post-stroke. Perhaps in the future, there could be research done on how well patients are

informed regarding PEG tubes and alternatives. Whether they are being educated on not only the benefits of them, but possible risks. This could be another probable reason for the higher rates of PEG tube placement in African-Americans.

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