Navigating Responsibility:
Examining the Shortcomings of Ghana's Stroke Care Infrastructure

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

I got a flat tire this morning. Driving to class, I hit a pothole and immediately saw that doomed flashing light on the side of my dashboard that tells you your day just took an unexpected turn. I called friends, asking how I go about fixing this as quickly and as cheaply as possible—after all I had a paper to write. Of course, they proposed Triple-A, but upon the mention, I quickly rejected that option. While this system was created exactly for this situation, I went about changing the spare myself. Now, I have never changed a flat before and ended up taking five times as long, and likely much lower quality, as a professional could have.

So, you may be wondering why I chose this route as it seemingly only makes things more difficult for myself? In my albeit limited experience, triple-A has consistently served as a catch-22. Waiting for hours on the roadside only to be hit with hefty charges for not meeting emergency service qualifications left a bitter taste, as many of my peers would agree. It's not that the services themselves are lacking; they're far more efficient at fixing a flat tire than I am. But navigating the caveats and paperwork associated with AAA makes it less appealing than handling things myself. I find it hard to place my trust in this company because of the systems in place supporting the services. So, I ended up ignoring this infrastructure, and did it myself. All day, I have been asking myself *what good is Triple-A if I cannot use it when it matters most*?

Rewording that question on a more general basis and unrelated to my car difficulties, I want to ask, what good is something if nobody can use it? In my situation, all that was lost was a little bit of time, but what happens when this inaccessible and untrusted system in place has more dangerous and implications? Thus is the case of stroke care in Ghana.

Stroke rates in Ghana are some of the highest in the world, while rehabilitation and recovery rates ranks as some of the lowest. Because of this disparity, stroke remains a prominent

cause of disability in Ghana (Agyemang et al, 2006; Sarfo et al., 2018). A universal challenge facing successful rehabilitation is accessibility—manifesting as policy constraints, cultural and religious values, financial burdens, and simple unconvinced attitudes towards the failing system that blocks individuals from obtaining the help they need (Donkor et al., 2014; Lynch et al., 2017). While the research and facilities may be newly in place in Ghana and ready for use, obtaining access to this infrastructure is frustratingly difficult. And so, stroke rates continue to rise, a phenomenon partly attributed to the public's lack of awareness of the condition and its care services (Donker et al., 2014; Patel et al., 2019).

In an effort to see how this system can be mended so that it can be impactful to its full extent, I evaluated multiple components of infrastructure as following Star's infrastructure framework. I argue that the negative outcomes seen in Ghanaian stroke infrastructure are the result of multiple parties' lack of understanding of stroke, and reluctance to assume responsibility for the crisis at hand. First, I will provide an overview of literature on the problems facing access to stroke care in Ghana. Then, I will analyze multiple components of the infrastructure in various situations that highlight the failures of the stroke care systems in place. In doing so, I will determine who is currently responsible for its shortcomings, and who should be taking on this responsibility instead. Finally, I will end with a discussion of how these findings can be further implemented to elicit positive change in Ghanaian stroke care and make steps towards an optimal infrastructure.

Literature Review

Stroke rehabilitation is a heavily researched topic and successful rehabilitation methods have been found to follow an intensive regimen. Residual stroke disability often manifests itself

as a lack of motor control, although severed neural pathways can be reconnected through physiological, occupational, and psychological therapy. However, these programs only work under the circumstances of frequent and long-term practice, as the nature of neural relearning requires these rehabilitation therapies to be consistent (Cook et al., 2005; Langhorne et al., 2011; Thomas et al., 2017). The plethora of research on rehabilitation techniques points to a consensus that the chance for rehabilitation increases when following a strict regimen of occupational, physio, and psychological therapy.

Stroke rate in Sub-Saharan Africa is extremely high, and the stroke infrastructure being put into place is fairly new compared to Western Europe and North America. Several scholars investigating stroke trends in Ghana, a country in Sub-Saharan Africa, have found extremely high stroke rates compared with the rest of the world, even in populations under 50 years of age (Agyemang et al, 2006; Sarfo et al., 2018). Literature surrounding stroke in Ghana frequently comes in the form of a call-to-action. The issues at hand are characterized in order to elicit change, and bring about public awareness of the situation, since community understanding of the disease by those at risk is limited (Donkor et al., 2014; Jenkins et al., 2018).

Various sources have identified a connection between socioeconomic status and stroke outcome. Internationally, developing countries produce lower outcome and higher risk rates, compared to developed countries (Lynch et al., 2017). Lynch et al. highlight a similar theme on a national level; lower socioeconomic classes exhibit worse stroke outcome than those of higher socioeconomic status. Prior research has found that access to rehabilitation services is reduced for those of lower socioeconomic status, allowing for the direct correlation between socioeconomic status, stroke outcome, and access to treatment after discharge to be drawn (Alawieh et al., 2018; Putman et al., 2007).

Public awareness of stroke has been linked to time-to-hospital response after stroke symptom onset, a predictor of stroke outcome. Time-to-hospital is a major predictor of stroke awareness, with longer wait times being linked to worse outcomes (Baatiema et al., 2021; Lee et al., 2021). In both the United States and in Ghana, the connection between community knowledge of stroke and time-to-hospital response has been shown; if someone can identify the tells on themselves or others, action can be taken sooner. Recognition of symptoms is not the only factor affecting the time to get hospital care; interpretation of these symptoms is just as important. In both countries, an ambulance or the emergency room is often not a person's first response, but variance lies in who is consulted initially (Baatiema et al., 2021, Patel et al., 2019).

Another issue created in the wake of this stroke crisis is the issue of caregiver burden. In the case of stroke, the role of caregiver almost always falls to family members. High rates of caretaker burden and burnout has been reported in Ghana, as is a common trend in stroke in general (Lutz et al., 2016; Watkins et al., 2020). Moreover, lack of support and communication by the hospitals in Ghana following discharge has been a trend observed by multiple sources and expressed by caregivers and patients as points of stress (Baatiema et al., 2021; Jenkins et al., 2016; Mohammed et al., 2023). Caregiver burnout is often attributed to not understanding how to help the person needing care and can be associated with high rates of depression and anxiety in the caregiver, and lower patient outcome as well (Lutz et al., 2016; Van Den Heuvel et al., 2001).

Although sources agree about the severity of the issue and the need for improved public awareness, research that details accountability for this failing infrastructure is lacking. A consensus has not reached to determine which parties are to blame for the insufficient rehabilitation rates, implying that this is a complicated system in which responsibility must be

dispersed. Additionally, while policy issues within the National Health Insurance Scheme are known, insurance coverage has not been brought forward with the responsibility one should expect, and thus insurance companies are not held accountable (Cook et al., 2005). And although the theme of a lack of public awareness is shown within the literature, this trend has not been fully explored in connection with socioeconomic status in order to drive change from the responsible parties.

I will be utilizing Star's infrastructure theory to conduct my analysis. Star's Infrastructure framework offers a unique view at complex systems, such as stroke care, by breaking it down into understandable components. Stroke systems in their whole are intricate networks that have many codependent parts and actors, which makes it an ideal candidate to be analyzed by infrastructure framework.

Conceptual Framework

I will be utilizing Star's Infrastructure framework to conduct my analysis; the stroke healthcare and rehabilitation systems of the Ghana will act as infrastructures. Infrastructures, as established by Star, are large and widely adopted systems whose functions are both crucial and unnoticeable to certain groups; these systems reflect the views and the bias of those people who create it, though this bias is often masked by the systematic processes within. Nine criteria of categorizing infrastructures are introduced in this framework, of which I will be using five.

The first key is that the infrastructure becomes visible upon breakdown. Next is transparency—in that "it does not have to be invented each time [...] but invisibly support those tasks" (Star, p. 381). The impact of the infrastructure due to its reach is evaluated by the reach and scope component. Links with conventions of practice go hand in hand with embodiment of

standards; this is the infrastructures ability to incorporate existing conventions and represent the goals it was created to do. Reach and scope is another component that I will be utilizing, as it reflects how impactful the infrastructure can be due to its reach.

Stroke infrastructure is a complicated system that is the product of many parties coming together with different goals, with each party integrating their biases into the infrastructure. A lot of this bias, I will argue, stems from a lack of understanding of stroke and its practices, so infrastructure is reflecting the lack of understanding. Using Star's framework, these biases are more easily revealed, and thus I will use this to expose that these are made by people who do not understand the importance and nuances of stroke rehabilitation.

Another piece of Star's infrastructure theory is the concept that one person's infrastructure is another's responsibility. This concept will be important in my analysis when determining accountability in each area of failure, detailing who currently bears the responsibility, who it should be, and who is ultimately in charge of making the change between these two.

Methods

The infrastructure of Ghana stroke care is complicated and intricate, so I will treat this topic as a case study. This will allow me to gather the wide variety of information necessary to look at this system and its critiques holistically. My case is time and space bounded, and so I will only gather infrastructure information after 2000 and from the Accra region of Ghana. My main secondary sources will be transcribed interviews, statistical data, surveys, medical papers, and calls-to-action papers. My primary sources consist mostly of policies, specifically the National Health Insurance Scheme. In my review of this literature, I examined my sources thoroughly for

mentions of issues in stroke rehabilitation, with a focus on accessibility, public perception, and demonstrated understanding that indicate the nonideal infrastructure.

Analysis

To analyze each of the key components of infrastructure as they are applied to Ghanaian stroke care, it is important to understand the current state of stroke and the possible undesirable outcomes associated with this. To do so, I will begin my analysis by addressing three unintended outcomes, and the first component of Star's infrastructure theory—visibility upon breakdown. When an infrastructure does not work as intended, the users become aware of the systems inner workings and its absence becomes noticeable. The most obvious indication of breakdown in Ghanaian stroke care is low rates of rehabilitation. As previously established, stroke incidence within Ghana is one of the highest in the world, and without high rehabilitation rates, stroke has become one of the primary causes of disability. A second undesirable outcome that has been brought on by this failed infrastructure has to do with the stress on those close to the stroke victim. Relatives tend to be caretakers and end up with enormous burden, as mentioned in the literature review. Therefore, mental health of those indirectly affected by stroke is an important outcome to consider when evaluating stroke infrastructure. The last indicator we established is socioeconomic disparities that occur because of faulty infrastructure. This manifests as socioeconomic trends to recovery rates, accessibility, attitude, and any other inequality brought on by socioeconomic status in stroke infrastructure. These effects—low patient outcome, caretaker burden, and socioeconomic disparities—are evidence of the failing systems, which has led us to become aware of the crisis that is stroke in Ghana. Via Star's infrastructure framework, we can begin to think about these problems regarding who can be held accountable, as one

person's infrastructure is another's responsibility. But the question remains, who is responsible for this multifaceted and failing entity? To answer this question, we will go into the causes of these poor outcomes and direct accountability through other components of infrastructure theory.

The issue of the infrastructure's transparency reveals the burden of caretaking as a result of the healthcare system's lack of educational resources for discharged patients. The existing system is one in which the task of caretaking falls to the family of the stroke victim, meaning family members must take time off from work to be a full-time supporter for their loved one until they are fully or partially rehabilitated. That is, unless outside assistance is present and affordable. This means family members must take time off work to be a full-time support for their loved one until they are fully or partially rehabilitated. Combining the knowledge of the unsatisfactory transparency of the healthcare systems in their support after discharge with the testaments that caregiver burnout is often due to not understanding how to help their loved one, it can be concluded that the high rate of caretaker burden is attributed to the unsatisfactory information given to the caregivers. This, in turn, has a poor effect on the patient's recovery as well as the mental health of the caretaker (Lutz et al., 2016, Van Den Heuvel et al., 2001) The responsibility has fallen on to the caregiver to learn how to care for their family member. Of the poor outcomes previously mentioned, the issue of burnt-out caretakers lends itself to worse patient rehabilitation, socioeconomic disparities for those unable to pay for help, and, of course, mental health of family members. The disconnect between the medical community's knowledge and the understanding of the direct caregivers is an issue in the infrastructure's transparency; instead of healthcare workers sharing how this is done best, caregivers must "relearn" and resort to their own methods to find what in-hospital nurses already understand. Therefore, the component of transparency in this case falls to the hospital stroke units to make more accessible

and comprehensive training programs for caretakers. By embracing stroke care's transparency, Ghanaian healthcare system will assume responsibility for caregiving quality and informing families, and in doing so relieve the caregiver burnout problem.

However, it is not only the caretakers that must have an understanding of stroke. The limited reach and scope of the infrastructure highlight the lack of understanding by Ghanaians as a result insufficient efforts by public health offices to inform the community. As mentioned in the review of literature, it has been established that increased time-to-hospital after stroke is a predictor of worse rehabilitation outcomes. It was also noted that public awareness of stroke is directly related to this time, since better symptom recognition can lead to making a quicker and better first action. Reporting low recognition rates of symptoms, as was reported by Donkor et al. in their 2014 investigation, not only puts the individual at risk, but limits the impact of the infrastructure itself since time-to-hospital is such a strong indicator of recovery outcome. By not having an adequate means of informing the public of the stroke crisis and available resources, the responsibility to discover one's own risk and learn about stroke falls to individuals. Ghana's Public Health Department should be held responsible for the failure of the reach and scope of the infrastructure. They have the resources and the platform to inform the public of symptom recognition and what to do, but by doing so unsuccessfully are inhibiting the infrastructure before it can help people.

Stroke infrastructure in Ghana is unique compared to western stroke care systems, in that there are important cultural and regional beliefs that affect the public's understanding of care. In failing to link the infrastructure to convention, cultural aspects are left out of consideration when trying to sway public awareness. One example of this was found by Baatiema et al., in their 2021 study that looked at stroke experience in Ghana. While determining deterrents of time-to-hospital

speed, it was found that of those that did not go directly to the hospital, the most popular actions were to seek an herbalist or a minister to pray (Baatiema et al., 2021). Jenkins et al. performed a study to understand the current attitudes related to stroke in Ghana and Nigeria, and found unique cultural themes, in addition to the tendency to visit herbalists instead of the hospital. While relatively minor, common responses of causes of stroke included "evil spirits/imagination," or that they were being "punished by Allah" (Jenkins et al., 2018). Regarding caretaker burden, responsible family members—without sufficient care training from hospitals—would often resort to herbalist and spiritualist practices of medicine as the primary rehabilitation method (Watkins, 2020). Stroke infrastructure has failed to link its practices and its style to fit into the current conventions of medicine in Ghana, and worse rehabilitation outcomes are experienced because of this. Baatiema et al. suggest the involvement of religious leaders in the education of stroke care, but this is just the beginning of how to make sure stroke care infrastructure abides with the culture. While it is beyond the scope of this paper to determine the best course of action for assimilating this European modeled infrastructure into Ghanaian culture with respect and full cultural understanding, I do understand that it is the responsibility of the Public Health Department of the Ghanaian government to initiate this change. The government taking responsibility for this combination of methods is important so that stroke care can be redefined by healthcare workers and communities in conjunction with their culture instead of rejecting either the cultural practices or Western medicine.

Affordable access to rehabilitation services are limited due to the National Health Insurance Scheme's (NHIS) failure to embody the standards of stroke rehabilitation,exposing a lack of understanding of stroke. It has been established that stroke is a leading cause of death and disability in Ghana, however the NHIS policies that cater to the target communities—those at

high stroke risk—do not cover most rehabilitation services, let alone the intensity of rehab required to have successful outcome (*Benefits Package*, 2023). Although procedures have been well developed to optimize chance of rehabilitation, the policy makers unwillingness to implement these treatments into their basic health plan reveal their ignorance towards stroke's importance and its practices. Without this understanding and urgency, the insurance companies cannot uphold the standards of the field in their own. Some might interpret this information as an effort of the companies to cover a wider range of diseases and services, however stroke is the leading cause of disability in Ghana, therefore its services should be made more of a priority. Instead, millions of Ghanaians are forced to choose between paying out of pocket, or not receiving rehabilitation care; the NHIS has shifted the blame and the guilt of this decision to the individuals and away from themselves. Due to the situation that stroke rehabilitation infrastructure is limited to those that can afford these services without the help of insurance, bad outcomes including lower rehabilitation rates and socioeconomic disparities arise. So, policy makers are failing to embody the standards of stroke care and must take responsibility for their part in this crisis by learning about it and applying this to their policies to increase access.

Conclusion

The negative outcomes that are currently experienced by stroke victims and their families have many causes, but breaking down the infrastructure of stroke care allows us to hold distinct parties accountable. In the spirit of transparency, the healthcare system and hospitals are responsible for passing on their knowledge of stroke care to familial caregivers to ease burden, encourage rehabilitation, and reduce socioeconomic rehab disparities. Public awareness of stroke, in the name of both symptom recognition and in meshing with cultural beliefs, must be

improved by the public health sector to optimize the impact of the systems in place. Insurance companies like NHIS must take responsibility for the limits their policies put on stroke rehabilitation and reevaluate this once they are fully informed of stroke's immense impact on their clients. It is time to take the responsibility off of the individual, and for these institutions to acknowledge the impact they are able to make on a nationwide crisis.

It is the goal of this paper to highlight the need for accountability in stroke care infrastructure in Ghana. Yes, stroke is a crisis in Ghana, but I hope that this paper incites hope in the knowledge that this is not a system beyond repair. Using the infrastructure framework is an excellent way to acknowledge the efforts of the many parties involved, while also exposing where it is lacking and how the community is affected by this. Although it was briefly mentioned, it is beyond the scope of this paper to go into the confluence of culture and stroke infrastructure, as these continue to adjust to one another. This paper was conducted using case study methods, and to get such an understanding of this relationship, ethnography would need to be utilized. Further research into the unique cultural experiences of stroke should be conducted to respectfully identify next steps for certain actors, especially those in government positions.

However, in a final testament to Star's infrastructure theory, the beauty of a complicated system such as stroke care is that it is fixed modularly—in pieces, not all at once. While there is still work to be done to figure out the best ways to assimilate culture and stroke rehabilitation, progress can be made by parties independently and improvement will still be seen. Positive interventions in any of these individual groups will see effective change to these poor outcomes, and hopefully be the beginning of a strong and reliable infrastructure that operates at its highest potential.

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