

COMMENTS AND OPINIONS

Stroke and COVID-19: The Value of Narrative Medicine

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ABSTRACT: Stroke and COVID-19 are both traumatic and life-altering experiences that are marked by uncertainty, fear, and medical intervention. The devastation that stroke and COVID-19 oppress on an individual and a population is well established, and these traumas are potentially magnified in the troughs of the COVID-19 pandemic. Furthermore, stroke has been shown to be a potential complication of COVID-19 infection, and while there is global controversy regarding this finding, it is undeniable that there are patients across the world presenting with both conditions concurrently. Thus, the topic of isolated stroke and the co-occurrence of stroke and COVID-19 amidst the pandemic both warrant considerable investigation on both a basic science level and a humanistic level. This opinion article advocates for a narrative medicine approach to better explicate the intertwining of stroke and COVID-19. Interviewing patients who presented with both stroke and COVID-19 as well as patients who present with stroke during the pandemic will provide the opportunity to gather and juxtapose individual illness experiences, including encounters with the health care system, relationship with care teams and care takers, recovery, and insights into the future. Creating, analyzing, and comparing such an anthology of illness narratives of the 2 patient populations will offer a unique understanding into the experience of different, yet over-lapping, medical traumas in an unprecedented time. With this deeper appreciation of patient accounts, the health care system can better recognize how to provide for future patients who present specifically with stroke or stroke and COVID-19. However, more broadly, this study can also afford insight into how the health care system can better provide for and support patients who present with complex diagnoses in the context of a complex healthcare system, which most probably will operate under the effects of the pandemic for time to come as well as other, future complicating factors.

Key Words: arteries ■ endothelial cells ■ fear ■ hemorrhagic stroke ■ pandemic

Stroke and COVID-19 are both traumatic and life-altering experiences that are marked by fear and medical intervention, both on an acute and chronic level. The devastation—physical, emotional, societal, and cultural—that both stroke and COVID-19 oppress on an individual and a population is well established. These traumas are potentially magnified in the troughs of the COVID-19 pandemic as health care encounters have been indisputably altered by the context of the ongoing global crisis. As such, experiencing a stroke in this time affords unique, complicating considerations which can be determining of outcome. Furthermore, stroke has been shown to be a potential complication of patients diagnosed with COVID-19.¹ However, there is global controversy surrounding this finding, and there has been significant dispute in the literature, both medical and

popular, as to the relationship between COVID-19 and stroke.² Numerous mechanisms have been proposed for the link between COVID-19 and stroke, with the leading theories being direct endothelial damage or infection by the virus. Notably, SARS-CoV-2 has affinity for the ACE-2 receptors expressed in the arterial smooth muscle cells and endothelial cells in the brain. Thus, the virus may damage intracranial arteries and cause vessel wall rupture.³ In May 2020, the World Stroke Organization reported the risk of ischemic stroke with COVID-19 as approximately 5%,⁴ and while hemorrhagic strokes are less common, cases have been reported.³ Thus, the topic of isolated stroke and the co-occurrence of stroke and COVID-19 amidst the pandemic both warrant considerable investigation on both a basic science and humanistic level.

The opinions expressed in this article are not necessarily those of the editors or of the American Heart Association.

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This creates an important need for a narrative medicine approach to understanding the intertwining of stroke and COVID-19 from the patient perspective. Narrative medicine is a theoretical and operative research approach developed about 35 years ago which stands to collect and interpret the patient's experience of their illness. Usually, narrative medicine studies are conducted through a semi-structured participant interview, which might comprise of protocol established guiding questions. Interviews are then analyzed for emergent themes. For example, references to specific triggers for psychological distress, barriers to health care access, or coping mechanisms. These themes are then compared across interviews to develop patterns of illness experience across individuals, often with the goal to identify areas of intervention. The patient's story may thus offer insight to the physical and psychological aspects of the illness. Furthermore, it can afford therapeutic processing, acceptance, and dignity of the disease for the patient, and for the clinician—a way to gauge overlap and incongruence in illness experience across patient populations. Narrative medicine studies have been conducted on a wide variety of diseases, including diabetes, pregnancy after liver transplantation, bipolar disorder, and pediatric leukemia. Examples of specific understandings and patterns unearthed from the narrative medicine approach include exploration of internalized stigmas regarding diagnoses, children's perception of disease, and socio-relational quality of service.⁵

There is a paucity of narrative medicine research pertaining to both stroke and COVID-19, a gap in the literature which further emphasizes the necessity of this line of investigation. Currently, narrative medicine stroke research has focused on poststroke treatment and rehabilitation, as well as on healthcare professionals' experience. In a multi-perspective qualitative study, Harrison et al⁶ explored patient, caretakers, and health professionals' experiences of psychological need and support post-stroke, both while in the hospital and immediately post discharge. They found that psychological expertise and protective factors (social and peer support, information provision) reduced the need for formal psychological support in all three populations. Another narrative medicine study by Krishnan et al⁷ examined stroke survivors' perspectives on their involvement in selecting a postacute care provider and their satisfaction with rehabilitation. They found that more than half the participants felt they were not involved in the selection of their postacute care and felt that their doctors made the decision, while the majority of patients were satisfied with their rehabilitation course. Finally of note, Dreyer et al⁸ sought to capture the experiences of nurses in acute and subacute rehabilitation of patients with stroke, ultimately delineating that getting to know the patient as a person, the importance of inclusion of caretaker and other relations' input,

and recognition of care team individuals' skills were all essential to care of the patient's needs.

There is similarly a lack of COVID-19 narrative medicine studies, although perhaps more understandably so given the timeframe of the ongoing pandemic. Even more so than is seen in stroke narrative medicine studies, there is a large emphasis on health care professionals' experiences regarding COVID-19. In one phenomenological study, Arcadi et al⁹ explored the experience of Italian nurses caring for COVID-19 patients, extracting four key themes: uncertainty and fear, alterations of perceptions of time and space, changes in the meaning of to care, and changes in roles and relationships. Xu et al¹⁰ investigated primary care practitioners' experience of COVID-19 epidemic control in China to find the main barriers to care to be inappropriate primary care provider scheduling, role ambiguity, inexperienced community workers, and insufficient cooperation. Some COVID-19 narrative medicine research has emphasized the patient experience. Moradi et al¹¹ studied the psychological disturbances of COVID-19 survivors and identified 3 themes: living in limbo, psychological distress behind the wall, and the psychological burden of being an infection carrier.

Therefore, with consideration of the available narrative medicine research regarding stroke and COVID-19, there are clearly gaps which demand further research. Namely, future narrative medicine studies must emphasize the patient experience during acute illness (stroke or COVID-19), including initial symptoms, hospital stay, and interactions with health care professionals, as well as emphasize the recovery phase outside of the clinical setting—that is, the patient experience of psychosocial factors, compounding stressors, and emotions postacute experience, among others. While investigating these avenues for stroke and COVID-19 separately will certainly yield fruitful understanding into patient experience and opportunities for advancement in care, a narrative medicine frame to the intersection of stroke and COVID-19 offers a plethora of insight, with even more roads on which to travel into a deeper comprehension of the human experience, with its infinite viewpoints, of these two diseases. The illness experience of patients suffering stroke and COVID-19, or stroke during the COVID-19 pandemic, is unique in history. Thus, in this research pursuit, together we can capture, for posterity, novel accounts during a time marked by the intertwining of unprecedented politics, culture, and science. It is in this anthology of individual stories that will emerge the patterns of families, communities, cities, and even nations as the global diseases of stroke and COVID-19 persist.

Before advocating for this lineage of research, it is important to acknowledge the limitations of narrative medicine research. Of course, each patient experience is as wonderfully and undeniably unique as the patient at its center. Therefore, in contrast to more controlled scientific studies on the effectiveness of medical measures, one

must be exceedingly weary not to generalize an illness experience to a population or to statements about the merits of clinical techniques. However, paradoxically, this important limitation of narrative medicine is also one of its greatest strengths: in each unique patient story is the opportunity to experience medicine from the eyes of the individual the medical system was created to serve—a chance to delve deeply into the fears, hopes, and lived-moments that so often get lost in generalizations. While narrative medicine does seek to weave patterns from unique patient stories, it is imperative to acknowledge the individualized nature of patient experience, as a limitation and a virtue.

Having offered an overview of narrative medicine and its role in stroke and COVID-19 research, what now follows argues for the necessity of narrative medicine research that captures the intertwining of stroke and COVID-19. There are 2 avenues of benefit for this research pursuit, which on a macro and micro level both contribute to preservation of care during health care emergencies. The first appears on a clinical level via retrospective insight into institutional preservation of stroke care during the pandemic. The second category of advantage offered by narrative medicine studies of this type is personal insight afforded to both patient and health care workers. Both of these branches of opportunity provided by a study of this type will weave back together to offer deeper understanding into the clinical actions, outcomes, successes, and failures on an institutional and personal level regarding stroke in the times of COVID-19. These findings can then provide insight into future planning for the preservation of stroke care during the ongoing effects of the COVID-19 pandemic as well as future health care crises. Furthermore, this narrative medicine approach to stroke and COVID-19 specifically may be broadened to give insight into the preservation of emergency care during the COVID-19 pandemic, which then may be applied to future preservation of emergency care during the ongoing effects of the pandemic and future health care crises.

The illness narratives collected from patient interviews will provide macro-level, clinical-insight regarding the preservation of stroke care during the COVID-19 pandemic. Such data might include time until care, protective measures, procedures and tests completed, time spent with health care workers, quality of care, and role of caretakers. This information will be invaluable in shaping protocol and clinical interventions in the current medical system, which will operate under the lingering effects of the COVID-19 pandemic for time to come, as well as prepare for other medical emergencies that might sweep the health care community. These future crises might be on a global or national level, but they might also be on a nodal level in which a health care system must adapt to preserve stroke care in the face of a localized emergency. For example, health care systems can better understand how to best communicate with patients and caretakers

when contact is strictly limited, how to optimize diagnostic tests, and how best to track recovery.

The second branch of benefit afforded by a narrative medicine approach to stroke and COVID-19 is personal insight for patients and health care workers to reflect on their experiences during an unprecedented time. This might be thought of as a micro-level benefit from the study, as individuals might better understand their actions during the COVID-19 pandemic as they related to preservation of care. Health care professionals might use the data collected as a point of reflection into their own clinical decision making during this time, a retrospective journey which can spur individual preparation for future, similar scenarios on a personal level. Furthermore, health care professionals and nonhealth care professionals alike can use the data collected to better understand how to advocate for themselves as patients and caregivers in the future medical system.

Thus, it is clear interviewing patients who presented with stroke during the COVID-19 pandemic will provide new, essential information. However, within this narrative medicine approach is the unique opportunity to interview patients who presented with stroke and COVID-19. The study of the latter illness experience provides all the insight and benefit previously discussed, but also will give the opportunity to hear stories never before told. The experience of having a stroke, even amidst an institutional health care crisis, is not a new one. However, the experience of having a stroke and COVID-19—that is having a stroke and the very virus that is ravaging the world—is one that has yet to be told. The story these patients hold is undeniably fascinating. From their words, the health care system and its individuals can learn not only how to preserve care, but how to care for the most vulnerable patients who find themselves at the intersection of a disease of old and a disease of new. It is in this overlap and the stories found within it that the global medical community can reflect, learn, and prepare to heal even the most complicated cases in the most complicated times.

ARTICLE INFORMATION

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