STUDY FACT SHEET FORM
Please keep this form in case you have any questions

Study Title: *Understanding the interplay between lifestyle factors and emotional distress for survivors with hemorrhagic stroke and their informal caregivers: A mixed methods dyadic natural history study*

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Who are we?
We are clinical researchers at the Integrated Brain Health Clinical and Research Program at the Massachusetts General Hospital (MGH). This study is sponsored by the Heitman Fellowship Young Investigator Award (MGH internal research grant).

What is the purpose of this study?
Hemorrhagic strokes (HS) account for less than a quarter of all strokes yet hold a significant amount of the disease burden of stroke. In addition to the physical toll of stroke, the social and emotional outcomes that affect both patients and their family caregivers is considerable. Despite these major physical and psychosocial issues that result from HS, there are also modifiable risk factors which can substantially contribute to health outcomes post-HS, including emotional distress management at lifestyle factors (diet, exercise, sleep). This is a research study designed to examine the longitudinal association between lifestyle factors and emotional distress among hemorrhagic stroke survivor-caregiver dyads from hospitalization to 1 and 3 months later. This information gathered from survey data will be used to further develop psychosocial interventions and inform treatment for patients of HS and their informal caregivers.

Who will take part in this research?
We are asking you to take part in this research because you are an adult (18+) HS survivor or caretaker of an HS survivor who was referred to us by the Neuro-ICU nursing team given your potential ability to participate in survey based research. We will recruit 80 HS survivor and caretaker dyads, approximately 160 people total, to take part in this research study. If a patient is likely to become eligible soon, we will start by enrolling the caregiver only.

How long will it take?
If you decide to join this research study, you will be asked to participate in a baseline interview conducted over 30 minutes to complete the study questionnaires. Two future assessment dates will occur as part of this study at 1 month and 3 months after first assessment. The latter two assessments will take 30 minutes each to complete.

What will happen if you take part in this research study?
If you decide to join this research study, you will complete the study questionnaire in the privacy of survivor rooms with the research assistant. At follow up timepoints (1 and 3 months later) participants will either be emailed the link to the questionnaires or will complete the assessment over the phone with the RA. Dyads will have the option to complete questionnaires in one 30-minute sitting or more sittings as needed. Clinical and demographic information from electronic

medical record will be collected throughout the study by the PI only after survivors have been enrolled in the study.

Why might you choose to take part in this study?
Although you will not directly benefit from partaking in this study, your participation may contribute to enhancing care for HS survivors and their caretakers.

Will you be paid to take part in this research study?
Financial compensation or remuneration will not be provided to study participants.

Do you have to participate in the study?
No. Participation in the study is completely voluntary. You are free to decline or withdraw at any time without consequences. Your decision will not change the medical care you receive at MGH or other Mass General Brigham hospitals now or in the future. There will be no penalty and you will not lose any benefits you receive now or have a right to receive.

What are the possible risks or discomforts involved from being in this study?
There are no foreseeable physical risks from this research study. Although unlikely, participants may feel uncomfortable completing various psychological questionnaires. Participants are free not to answer any and all questions, and additionally you can drop out of the study at any time without any consequences. As in any research study, there is a small risk that confidentiality may be breached. All efforts to minimize this risk will be taken. In the unlikely event that participants become suicidal at any point during the duration of the study, the research assistant will contact the PI and appropriate clinical intervention will be executed (including risk assessment, safety planning with survivor and care-partner, and referral to a higher level of care as necessary).

How is my confidentiality and data protected?
All study staff have been trained in responsible research conduct through a CITI course at MGH. The research assistant has also been trained on the importance of maintaining confidentiality, and the assignment of ID numbers. All data will be kept confidential, under lock-and-key, accessible only to trained study staff. Participants' data will be identified by ID number only, and a link between names and ID numbers will be kept separately under secure electronic hospital firewall.

What if I have questions about my rights as a research participant?
If you'd like to speak to someone not involved in this research about your rights as a research subject, or any concerns or complaints you may have about the research, contact the Mass General Brigham IRB at (857) 282-1900.

We are required by the Health Insurance Portability and Accountability Act (HIPAA) to protect the privacy of health information obtained for research. This is an abbreviated notice, and does not describe all details of this requirement. During this study, identifiable information about you or your health will be collected and shared with the researchers conducting the research. In general, under federal law, identifiable health information is private. However, there are exceptions to this rule. In some cases, others may see your identifiable health information for purposes of research oversight, quality control, public health and safety, or law enforcement. We

share your health information only when we must, and we ask anyone who receives it from us to protect your privacy.