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MEANING-MAKING IN THE ABSENCE OF A STROKE CAUSE: A QUALITATIVE STUDY OF ISCHAEMIC STROKE-AFFECTED INDIVIDUALS' AND FAMILIES' EXPERIENCES OF STROKE AETIOLOGICAL INVESTIGATION

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Background and aims: Recurrent stroke impacts nearly half of stroke-affected individuals. Identifying underlying aetiology is key for secondary prevention and for informed health decisions. Aetiological investigations often continue months after discharge, and almost one-third never receive a clear cause (cryptogenic stroke). Early public engagement highlighted the anxiety and uncertainty this creates for stroke-affected individuals and families. This study explored their experiences of being investigated and learning the cause of their stroke.

Methods: Adults (≥ 18 years, English-speaking), 3-12 months post-ischaemic stroke, and family members, were recruited from three UK stroke units using maximum-variation sampling. Family members were eligible if supporting a relative during investigations. Semi-structured interviews were conducted online or by telephone, transcribed verbatim, anonymised and analysed iteratively and reflexively using Thematic Analysis. Analysis is ongoing and will be completed in February 2026.

Results: Eighteen stroke-affected individuals (9 female, median age 68.5 years) and four family members (3 spouses, 1 child) participated. Most reported not knowing the definite cause of stroke. Emerging candidate themes encompassed personal meaning-making around cause of stroke and include: 1) speculation about cause and lifestyle impact; 2) fatalism and acceptance in coping with cryptogenic stroke; 3) self-blame and attributing stroke to lifestyle in the absence of a cause; 4) fear, caution and lack of control regarding recurrence and prevention.

Conclusions: Preliminary findings suggest cryptogenic stroke elicits diverse responses from emotional turmoil and indifference to acceptance and positive lifestyle change. Understanding these

experiences can inform tailored communication and support during aetiological investigation.

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