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Patient involvement in an assessment of the management of sudden onset severe headache presenting to the Emergency Department

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INTRODUCTION

Sudden onset severe headache is usually caused by a primary headache disorder but it may be secondary to a more serious problem, such as subarachnoid haemorrhage. Subarachnoid haemorrhage occurs when a weakened blood vessel supplying the brain suddenly bursts. Very few patients who present to an Emergency Department with headache have suffered a subarachnoid haemorrhage, but early identification is important to reduce the risk of death or severe disability. Diagnosis can be difficult in alert, neurologically intact patients who may present with symptoms typical of more common headache diagnoses, such as migraine. UK guidelines recommend non-contrast computed tomography (CT) of the head followed by lumbar puncture to exclude subarachnoid haemorrhage. However, guidelines pre-date the introduction of more sensitive CT scanners and lumbar puncture can cause complications such as headache, low back pain and infections.

A systematic review was undertaken to assess diagnostic strategies for excluding subarachnoid haemorrhage in neurologically intact adult patients presenting to hospital with a sudden onset severe headache. Capturing the perspective of patients was an important part of the research, to help the team understand the experiences and preferences of patients and explore the acceptability of different diagnostic pathways.

METHODS

A patient collaborator with experience of presenting to an Emergency Department with a sudden onset severe headache was involved throughout the project. The patient collaborator commented on drafts of the funding proposal, protocol and final report; highlighting relevant outcomes to be considered in the review and his own preferences regarding aspects of the care pathway. The patient collaborator also commented on plain English summaries of the project. Three additional patients who presented to the Emergency Department at Leeds Teaching Hospitals NHS Trust with a sudden onset severe headache were recruited to an advisory group; they commented on the draft protocol and gave their perspective on the results of the review.

Meetings with the patient collaborator and patient advisory group members were undertaken face-to-face or via telephone or Zoom videoconferencing software, according to patient preference and COVID-19 restrictions in place at the time of the meetings.

RESULTS

The patient advisors provided comments on several aspects of the results of the review. The characteristics and comorbidities of the patients involved in this project were varied, however, their concerns and preferences were generally consistent.

Patients were reassured by the very high diagnostic accuracy of CT for detecting subarachnoid haemorrhage. The systematic review identified four studies assessing the diagnostic accuracy of CT undertaken within six hours of headache onset that were suitable for pooling; pooled sensitivity was 99% and specificity was 100%, although sensitivity beyond six hours was considerably lower (≤90%; two studies).

Patient and clinician advisory group members emphasised the importance of involving the patient in the decision to undertake further tests after a negative CT scan result; communicating the level of uncertainty and the possibility of adverse effects associated with subsequent tests should aid the decision-making process. The systematic review identified three studies assessing the diagnostic accuracy of lumbar puncture following a negative CT result that were suitable for pooling; pooled sensitivity was 100% and specificity was 95%. Two studies reported that 5-10% of patients returned to hospital after lumbar puncture with adverse events.

Patients stated a preference for lumbar puncture to be implemented on an ambulatory basis, when considered necessary. However, there were no studies assessing the use of lumbar puncture in this setting and clinician advisory group members highlighted variation in current practice. Therefore, further research on the safety and acceptability of ambulatory lumbar puncture was recommended.

CONCLUSIONS

Patient involvement was an important aspect of this project, enabling researchers to understand the care pathway for the management of sudden onset severe headache from a patient's perspective. Their input added context to the review findings and highlighted their preferences regarding how sudden onset severe headache is managed in the Emergency Department.

Systematic review registration: The protocol was registered on PROSPERO (CRD42020173265).

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A full detailed report is available on the Centre for Reviews and Dissemination website: https://www.york.ac.uk/media/crd/Sudden-onset-severe-headache-final-report.pdf