Abstracts

Articles appearing in the June 2018 issue

Reflections on translation: Views of participants in a multisite Canadian CCSVI clinical trial

Background We sought to characterize the perspectives of participants in Canada's phase I/II chronic cerebrospinal venous insufficiency (CCSVI) clinical trial prior to and after the disclosure of trial results.

Methods This was a researcher-administered survey of individuals who participated in Canada's CCSVI trial (Clinicaltrials.gov, NCT01864941) about their (1) motivations for participating, (2) understanding of the trial process, and (3) perspectives on the social value of the trial.

Results A total of 63 participants completed the survey. Participants were motivated to participate by altruism (mean score = 4.56 out of 5) and a desire to access the intervention in Canada (mean score = 3.63 out of 5). Many participants expected medical benefits, such as partial disease reversal (mean score = 3.32 out of 5). Participants felt strongly that the crossover trial design promoted fairness (mean score = 4.65 out of 5). Participants' familiarity with the CCSVI controversy increased significantly after the results were revealed ($p = 0.0001$). Despite negative trial results, participants still felt that the trial was an appropriate use of tax dollars (mean score = 4.68 out of 5). Many (38%) upheld the belief that further CCSVI research is necessary (responses of 4 out of 5 or higher).

Conclusions There is a strong movement in science today to ensure that research agendas reflect the perspectives of multiple stakeholders, including research participants. While previous work suggests that negative findings adversely affect trust in science, the perspectives of participants in this study demonstrate that good trial design and resilience can prevail over expected tensions.

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Neuroimaging abnormalities in patients with Cowden syndrome: Retrospective single-center study

Background We retrospectively reviewed the neuroimaging findings of patients with Cowden syndrome and determined their frequency in a single cohort.

Methods Electronic medical records were queried from January 1999 to January 2017 to identify patients who fit the clinical criteria for diagnosis of Cowden syndrome with or without a documented *PTEN* mutation. Patients with brain MRI examinations were then identified.

Results We retrospectively identified 44 patients with Cowden syndrome, 22 of whom had neuroimaging for review. Eleven (50%) had Lhermitte-Duclos disease, 4 (18.1%) had meningiomas, 13 (59.1%) had at least one developmental venous anomaly, 3 had cavernous malformations, 2 had evidence of dural arteriovenous fistula, 7 had increased white matter signal abnormalities relative to age (31.8%), 4 had prominent perivascular spaces, cerebellar tonsillar ectopia was present in 7 of 21 (33.3%), and 1 had cortical malformation.

Conclusions It is important to recognize that in addition to Lhermitte-Duclos disease, other intracranial findings such as multiple venous anomalies, meningiomas, greater than expected white matter signal abnormality, prominent perivascular spaces, and cortical malformations may warrant a thorough evaluation for Cowden syndrome in the appropriate clinical setting. We further recommend that this broader spectrum of intracranial abnormalities be considered for addition to the Cowden syndrome diagnostic criteria at the time of next revision.

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Practice Current

Our survey on "When do you suspect autoimmune encephalitis and what is the role of antibody testing?" has received over 1,000 responses from over 80 countries. Explore this topic and others on our redesigned website: compare your practice with peers and see survey results displayed on an interactive world map.

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