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A qualitative study of families' experiences with medical assistance in dying (MAiD) in Nova Scotia

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Background: MAiD became legal in Canada in 2015, with Bill C-14 delineating eligibility criteria and access. Previous research found families are intimately involved with decision-making, with conflicting perspectives on how they cope.

Our study sought to learn about the experiences of family members, and determine what supports might be beneficial to improve MAiD delivery and aftercare. **Methods:** We conducted hour-long semi-structured interviews with 20 family members of individuals who had MAiD. Interviews took place by telephone or virtually via MS Teams, and transcripts were analyzed using an iterative coding process and thematic analysis. **Results:** Prominent themes emphasized the importance of respecting autonomy, decision-making, and allowing people to regain a sense of control, particularly with so much taken away.

The death itself was described as peaceful. Interviewees were overwhelmingly filled with relief and gratitude for being able to respect the individual's wishes.

Interviewees spoke of importance of support for themselves, and the desire to build a network of individuals with similar experiences; to share their stories, grieve together, and support the next generation. **Conclusions:** These results will help improve MAiD delivery and aftercare in Nova Scotia, by informing, developing and enabling access to resources for individuals who accompany a family member on their end-of-life journey.

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A systematic review of the incidence and prevalence of Neurofibromatosis type 1 and 2

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Background: Neurofibromatosis 1 and 2 (NF1 and NF2) are autosomal dominant genetic disorders caused by mutations in tumour suppressor genes. **Methods:** We conducted a systematic review of the incidence and prevalence of NF1 and NF2 in OVID Medline, OVID Embase, Web of Science, and Cinahl. We included studies until February 19, 2021, that identified cases based on established criteria. Studies were appraised for quality using the Joanna Briggs Institute Prevalence Critical Appraisal tool. Pooled incidence and prevalence rates were estimated through meta-analysis. **Results:** Of 1,936 studies, 1,866 were

irrelevant after title and abstract screening. Sixteen of 69 studies with full text assessment were included for full review: 13 regarding NF1 and 6 regarding NF2. Incidence rates for NF1 and NF2 ranged from 1/11,494 to 1/1,871 and 1/62,185 to 1/33,000 respectively. Prevalence rates for NF1 and NF2 ranged from 1/6,238 to 1/1,001 and 1/600,000 to 1/56,161 respectively. Meta-analysis will be presented at the conference. **Conclusions:** An accurate estimate of the incidence and prevalence of NF1 and NF2 will offer more insight into health resource allocation. Increased funding and resources for the development of early diagnostic and treatment tools for NF1 and NF2 may improve the quality of life of patients.

NEURORADIOLOGY (CSNR)

MS/Neuroinflammatory Disease

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Random Neural Network Features in Patients with Aggressive Multiple Sclerosis Undergoing Autologous Hematopoietic Stem Cell Transplant

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Background: Objective markers of disease progression are needed for patients with multiple sclerosis (MS). Increased randomness in neural networks is hypothesized to be an important cause of morbidity that can be objectified using graph theory. Methods: We use voxel-based structural similarity determined from T1-weighted MRI scans of 23 patients with MS receiving autologous stem cell transplant (ASCT) to compute cortical covariance network parameters. We examine associations between measures of cortical integration or segregation and biochemical/clinical measures of cortical health or function using Spearman correlation coefficients. P<0.05 was considered significant. Results: Path length increase was associated with markers of greater inflammation (ρ=0.56,P<.046) at baseline and reduced Naa/Cr ratio (P<.041) at 12 months. Reduced lambda was associated with markers of greater grey matter atrophy (p=0.55,P<.019) after 12 months and lower cognition (ρ=0.56,P<.008) at 12 months. Reduced clustering was associated with higher neurofilament (ρ=-0.68,P<.010) at baseline, greater white matter atrophy (p=0.62,P<.006) after 12 months, lower 2-second PASAT performance (ρ=0.56,P<.011) at baseline, and reduced Naa/Cr ratio (P<.001) at 12 months. Conclusions: Reduced cortical integration and segregation (random network features) co-occur with unfavourable markers of cortical health and function in patients with MS receiving ASCT. Network features show promise as important longitudinal markers of patient status and progression.