

Title: Integrating Palliative Care in a Rett Program: An Educational Plan

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Statement of the Problem: Parents who have children diagnosed with Rett Syndrome need their child's teams to support them in their long journey managing severe disability. Rett Syndrome programs and providers across the country lack palliative care resources and knowledge.

Background: A database literature search was conducted from 2010-2021 in PubMed, Google Scholar, and CINAHL. None of the eight articles identified focused on palliative care, but instead on the challenges and hardships faced within this disorder. Additional research points to the limited resources available to meet the challenges presented as this population ages.

Purpose: To provide education to Rett Syndrome specialists on the need and benefits of palliative care as a vital component to the interdisciplinary clinic team.

Methods/Measures: A 15-minute zoom palliative care educational session was presented to 26 providers within the "North America Clinic Network Meeting" hosted by the International Rett Syndrome Foundation in May 2021. A palliative care resource card consisting of palliative care definition, resources, common phrases used in palliative care and points in care to refer, was provided to attendees. Providers, mostly comprised of physicians and nurses, completed a pre/post presentation 4-item google survey.

Findings: Eighteen providers completed the pre-survey; 10 the post-survey. There was a significant increase (3.7/5 pre; 4.4/5 post on a 1-5 scale) in the provider's self-reported level of palliative care knowledge. Providers' willingness to refer patients to palliative care, when their care becomes more complex, doubled after the provided education (40% pre; 80% post). Providers were 30% more likely to consider themselves the palliative care provider on the team following the educational session (50% pre; 80% post).

Conclusion: Providing palliative care education to Rett Syndrome providers may increase the referral rate to palliative care services, increase providers' knowledge about palliative care, and encourage application of these skills to their own patients.