

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

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## STATEMENT OF PROBLEM

- Those diagnosed with Rett Syndrome need support managing their severe disabilities.
- Rett Syndrome programs and providers lack palliative care (PC) resources and knowledge.

## **BACKGROUND**

- Database search PubMed, Google Scholar, CINHAL (2010-2021)
- No articles found on PC in Rett Syndrome.
- Research focused on challenges, hardships, and limited resources for this aging population.

## **OBJECTIVE**

To provide education to Rett Syndrome specialist on needs and benefits of PC as a vital component to the interdisciplinary clinic team.

## SPECIAL THANKS

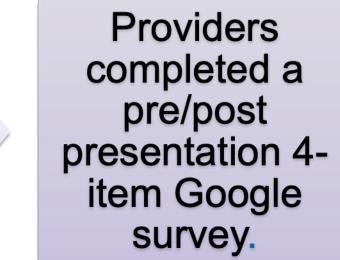
Tim Benke, MD Denver, CO



### **METHODS**

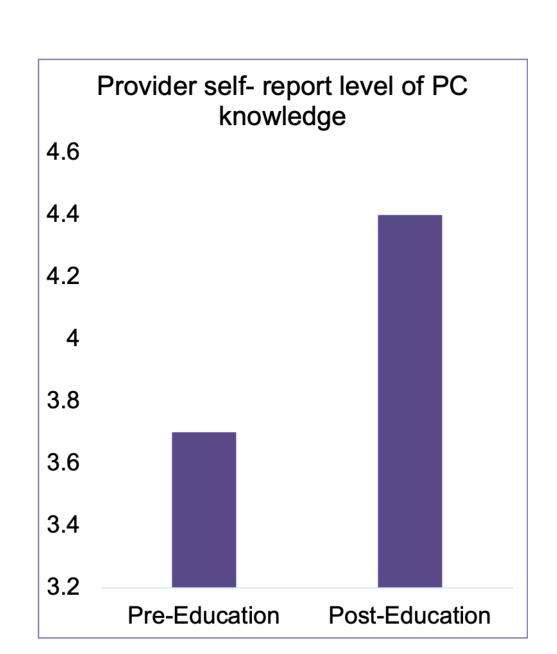
A 15-minute Zoom PC education session was presented to 26 providers within the "North America Clinic Network Meeting" hosted by the International Rett Syndrome Foundation in May 2021.

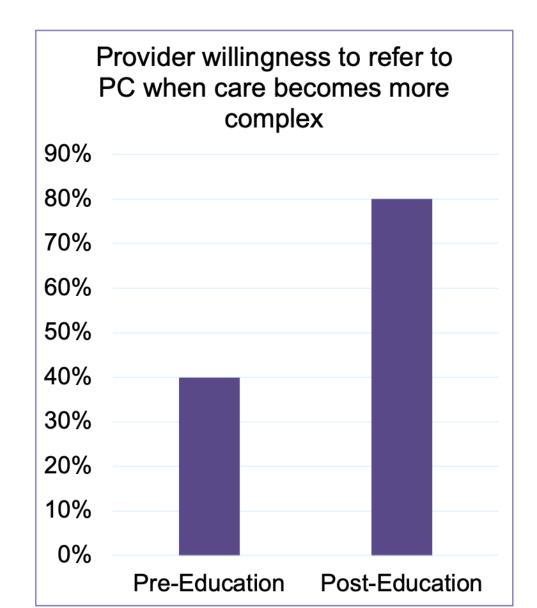


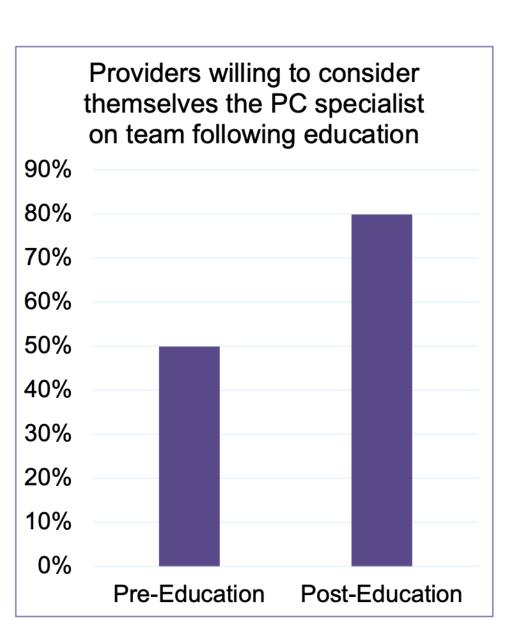


# PALLIATIVE CARE-RETT DEFINITION OF PALLIATIVE CARE Specialized medical team who focuses on quality of life for patients with serious diseases. They support family and work with patient's care team to ensure care at all stages for patient and family. COMMUNICATION PHRASES 1 This is what I have heard from you... 1 I know how much you were hoping for good news and... Of all that is happening right now, what is the hardest part to deal with? REFERRAL CRITERIA Diagnosis of chronic disease Uncontrolled Pain Discuss goals of care, medical decision making Multiple hospitalizations in a few months End of life care needed Emotional and familial support needed RESOURCES CONTACT INFORMATION Tristen Dinkel, BSN, RN, CPN, CNRN Phone-720-777-7455 Email- tristen.dinkelechildrenscolorado.org

## **RESULTS**







## **CONCLUSIONS**

Providing PC education to Rett Syndrome providers may increase the referral rate to PC services, increase knowledge about PC and encourage application of skills to patients.

## LIMITATIONS

- There are few PC resources for Rett Syndrome support.
- There is a need for financial support within Rett Programs for more PC providers.

## REFERENCES

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