

Chapter 8

Family–Centered Telehealth Supporting Motor Skills and Activity in Individuals With Rett Syndrome

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ABSTRACT

Rett syndrome is a rare genetically caused condition associated with severe disability and impaired motor functions. Local therapists typically see small numbers of affected individuals, and this limits their capacity to gain experience. Telehealth is being used increasingly to counter poor access to rehabilitation services. Moreover, there is a need to develop management plans that support individuals with Rett syndrome over their lifespan. Three projects in which telehealth support was provided by therapists experienced in Rett syndrome and supported by available local resources are presented in this chapter. The three projects responded to locally identified needs in a cost-efficient way and empowered those working with people with Rett syndrome to maintain and improve their clients' physical function and activity. This chapter will discuss the conceptual underpinnings of delivering a service using a telehealth approach and describe the results and the strategies implemented in the projects mentioned above.

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INTRODUCTION

Remote Telehealth Services

Telehealth services (THS) are the goal-oriented use of various remote technology applications, such as mobile phone, computer, computer sharing, and television applications, to access individuals who need rehabilitation services. Telehealth services are managed by professionals and have explicit goals as with other rehabilitation (Salminen et al., 2016). The development of THS has responded to the need to reduce medical costs, to provide professional expertise with rare syndromes from a central location, and to counter long distances to access health services, especially for those living in rural areas (Patel et al., 2012). These challenges have challenged the development of cost-effective and technology-based solutions to provide remote health care and rehabilitation. Telehealth services might help to solve the problems related to patient access to rehabilitation, therapies, or physician expertise. Such technology could extend or replace some outpatient care or rehabilitation processes (Calouro et al., 2014). There are many areas where THS have been found useful in evaluation (Mani et al., 2017) and therapeutic settings, including for cardiac patients (Anttila et al., 2019), neurological rehabilitation (Jagos et al., 2015), orthopedics (Bell et al., 2019), improvement of adaptive skills (Caprì et al., 2021) and physiotherapy (Gal et al., 2015). Most of these intervention projects have been implemented with individuals with less severe disability. The question is, can individuals with severe disability, such as those diagnosed with Rett syndrome (RTT), benefit from technologically advanced medical and therapy services, such as THS?

Rett Syndrome (RTT)

RTT is a neurological disorder mostly found in females and is caused by a mutation in the MECP2 gene (Amir et al., 1999). The child with RTT has apparently initial normal psychomotor development during the first 6-18 months but then presents with regression in language, gross motor, and manual skills. The hallmark of the disease includes the onset of repetitive stereotypical hand movements which appear during the regression period (Neul et al., 2010). Comorbidities associated with RTT usually include the development of scoliosis by approximately 80% of those diagnosed (Downs et al., 2016) and seizures occurring in 50%-85% of individuals (Glaze et al., 2010). Many females with RTT will survive into adulthood (Anderson et al., 2014). Therefore, setting achievable long-term therapeutic goals for these individuals over the lifespan is vital (Cass et al., 2003). Therapies for RTT have had some success when delivered in clinic (Budden, 1995) or school settings (Elefant, 2001). Several studies have investigated the application of an enriched therapeutic environment to small samples of individuals with RTT. Although evidence is limited, these examples suggest that programs can maintain and even increase gross motor function and wellbeing (Downs et al., 2018; Lotan et al., 2012). Recent reviews on rehabilitation interventions show that individuals with RTT can achieve functional improvements in gross motor, fine motor, and communication skills (Amoako & Hare, 2020; Fonzo et al., 2020; Lim et al., 2020). Cumulative evidence suggests that intensive, high-quality, ecologically focused interventions at a young age can yield significant positive results. Therefore, most research projects, including those targeting people with RTT are aimed at participants at younger ages (Ramey & Ramey, 1998).

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