# The caregiver's experience: Deciding what, when, and how much to tell an individual with Williams syndrome

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Background: Williams syndrome (WS) is a genetic disorder caused by a microdeletion on chromosome 7. The most prominent features of WS are cardiovascular problems, a highly social personality, and characteristic facial features. With a prevalence rate of 1 in 10,000 and an easily ordered diagnostic test, more clinicians are recognizing WS, leading to an increase in diagnoses at younger ages. In turn, caregivers face the challenges of what to tell their family member about why they are different and deciding how to explain WS to the rest of their family, friends, and community. Parent to child communication is a relatively understudied topic in genetics, especially regarding specific syndromes. Broad studies have demonstrated that presenting the information at an age-appropriate level and maintaining open communication allows time for children to process the information, but little is known about the caregiver's experience during this time. Purpose: The current study aims to explore the caregiver's experience deciding what, when, and how much to tell their family member with WS, what factors influenced their decisions, and their perceived success of the experience as a whole. Methods: Primary caregivers of individuals with WS were identified through the Williams Syndrome Registry and surveyed via an online survey. Survey responses were analyzed for frequency of answers; short answer questions were coded and categorized into themes. Results: The majority of caregivers (92%) reported experiencing one or more challenges in discussing the diagnosis of WS with their family member. The highest reported (54% of respondents) challenge was the level of understanding the individual with WS demonstrated both during and after the conversation. Despite the challenges, 83% of caregivers reported feeling satisfied with their disclosure experience overall.