

# Geographical Barriers in the Care of Rare Disease Patients using Telehealth

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## Description

Rare diseases, often referred to as orphan diseases, are conditions that affect a small percentage of the population. Despite the vast diversity of these diseases, they share a common challenge: patients living with them often struggle to access specialized care due to their remote location or the limited availability of healthcare professionals with expertise in these conditions. This challenge is especially pronounced for individuals residing in rural or underserved areas where medical resources are scarce. However, the advent of telehealth has opened new methods for overcoming geographical barriers in healthcare delivery, offering innovative solutions to ensure that rare disease patients receive the care they need, regardless of their location. Rare diseases, by definition, affect fewer than 200,000 individuals in the United States or less than 1 in 2,000 individuals in Europe. This rarity can result in a lack of awareness and expertise among healthcare providers, making diagnosis and treatment particularly difficult. The rarity also means that specialized care is often concentrated in academic centers or major metropolitan areas, leaving patients in remote or rural regions with limited access to the healthcare professionals who are trained to manage these complex conditions. The cost of traveling to these specialized centers is often prohibitive and for some patients, traveling long distances can be physically taxing, particularly for those with conditions that are difficult to manage. In addition to geographical barriers, rare disease patients frequently face delays in diagnosis. On average, patients with rare diseases endure a lengthy diagnostic journey, which can take years in some cases. This delay in diagnosis is often due to the lack of familiarity with the disease among general practitioners and the absence of readily available diagnostic tools. When patients do eventually receive a diagnosis, the road to appropriate treatment can be equally challenging, as many rare diseases lack well-established treatment protocols.

## Telehealth geographical barriers

Telehealth refers to the use of telecommunications and virtual technology to provide healthcare services remotely. This can include video consultations, remote patient monitoring and the use of mobile apps to track symptoms. The rise of telehealth has been transformative, particularly for patients with rare diseases who are located in rural or underserved areas. Telehealth allows

these patients to connect with specialists, access second opinions and receive ongoing management of their conditions without the need for frequent travel. One of the most significant advantages of telehealth is its ability to bridge the gap between patients and healthcare providers, regardless of geographic distance. Through virtual consultations, rare disease patients can access care from specialists who may be located thousands of miles away. This is particularly valuable when patients need to consult with experts who have experience in managing their specific condition, something that might not be available locally. Telehealth also enables patients to receive follow-up care and monitoring without needing to make regular visits to a clinic or hospital. Many rare diseases require long-term management and telehealth provides a way for patients to stay in touch with their healthcare team, track their symptoms and make necessary adjustments to their treatment plans. This continuous care is vital for patients whose conditions may be progressive or whose treatment requires frequent adjustments.

## Expanding access to specialized care

Telehealth not only facilitates consultations with specialists but can also expand access to multidisciplinary teams. Many rare diseases require the input of various healthcare professionals, such as geneticists, neurologists, endocrinologists, or cardiologists. In rural areas, access to such specialists is often limited, but telehealth allows these experts to collaborate and provide comprehensive care without being physically present at the same location. For *e.g.*, a patient living in a remote area with a rare genetic disorder may initially consult a general practitioner who suspects the condition but is unsure of the diagnosis. Through telehealth, the patient can quickly be connected with a geneticist who can review medical records, interpret test results and provide a diagnosis without requiring the patient to travel to a specialized center. Additionally, the patient can be connected to other specialists who can offer insights into managing the disease and its various symptoms. Telehealth can also be a valuable tool in facilitating clinical trials for rare diseases. Clinical trials are a critical component of advancing treatments for rare diseases, but enrolling in trials often requires patients to travel to major medical centers, which can be a significant barrier for those in remote locations. With the integration of telehealth, patients can participate in clinical trials from home, reducing the need for travel and making it

easier for researchers to recruit a more diverse patient population. This, in turn, can lead to more robust data collection and more effective treatments for rare diseases. Another critical aspect of telehealth in managing rare diseases is its ability to provide educational resources and support to patients and caregivers. Patients with rare diseases often face significant

emotional and psychological challenges, particularly when they feel isolated due to the rarity of their condition. Telehealth platforms can offer virtual support groups, counseling services and educational seminars, allowing patients to connect with others who share their experiences.