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What Motivates Patients to Continue Taking Tolvaptan: A Qualitative Study on Adherence and Patient Voices in South Korea

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Objectives : Autosomal dominant polycystic kidney disease (ADPKD) is a genetic disorder that leads to kidney dysfunction. Tolvaptan is the first approved treatment to slow its progression, but disruptive adverse effects, such as excessive thirst and frequent urination, hinder adherence. While its clinical efficacy is well-documented, little is known about the psychosocial and cultural factors shaping tolvaptan adherence in South Korea.

Methods : Autosomal dominant polycystic kidney disease (ADPKD) is a genetic disorder that leads to kidney dysfunction. Tolvaptan is the first approved treatment to slow its progression, but disruptive adverse effects, such as excessive thirst and frequent urination, hinder adherence. While its clinical efficacy is well-documented, little is known about the psychosocial and cultural factors shaping tolvaptan adherence in South Korea.

Results : Despite significant adverse effects, most participants adhered to tolvaptan, motivated by the potential to delay dialysis and transplantation. A significant factor influencing tolvaptan adherence was the psychological motivation to delay potential future worst-case scenarios for both patients and their families, rather than deriving immediate symptomatic relief or perceivable therapeutic effects. Trust in medical professionals, as well as anecdotal evidence from family members and online communities, has given rise to conjectures regarding future outcomes, thereby incentivizing participants to pursue medication. The anticipation of mitigating future risks was identified as the primary motivator for patients to endure the current discomfort, severe adverse effects and financial burden associated with the medication. Therefore, psychosocial factors were found to have a greater influence on tolvaptan adherence than its pharmacological efficacy.

Conclusions : Adherence to tolvaptan in ADPKD patients is shaped by a complex interplay of personal, familial, and medical cultural factors. Adherence to tolvaptan in ADPKD patients is shaped by a complex interplay of personal, familial, and medical cultural factors.