

“Chasing Hope”: Parents’ Perspectives on Complementary and Alternative Interventions for Autism Spectrum Disorder Children in Kazakhstan

Authors : Sofiya An, Akbota Kanderzhanova, Assel Akhmetova, Faye Foster, Chee K. Chan

Abstract : Healthcare, education and social support for children with autism in Kazakhstan has been evolving and transforming over the last three decades. There is still limited knowledge of the use of complementary and alternative medicine by families caring for autistic children in this post-Soviet region. An exploratory qualitative focus group study of Kazakhstani families was carried out to capture and understand their experiences of using complementary and alternative (CAM) medicine. A total of six focus groups were conducted in five cities across the country including Nur-Sultan, Almaty, Kyzylorda, Karaganda and Taraz. The perceived factors driving the availability, choice, and use of complementary and alternative medicine by families of autistic children in the country were distilled and evaluated. The data collected was analyzed using a framework analysis and themes and subthemes were developed. Two major themes stood out. The first was the “unmet needs”, which relates to the predisposing factors that motivate parents to CAM uptake, and the second was the “chasing hope”, which relates to the enabling factors that facilitate parents’ uptake of CAM. Fear of missing out (FOMO) is a latent underlying motivation underscoring these two themes as well. Parents of autism spectrum disorder (ASD) children in Kazakhstan have to deal with many challenges when seeking treatment for their children with ASD. They are prepared and resort to try out whatever CAM interventions available. The motivation and rationale of choice of use is driven by the lack of options and the hope of any potential positive outcome rather than from rational decisions based on efficacy or the evidence-based data of CAM. Parents get desperate and are willing to try CAM regardless of and independent of their cultural and belief systems and they do not want to miss out just in case it might work. This study also gives an international and cross-cultural perspective on the motives, choice and practice of parents with ASD children using CAM in Kazakhstan, a Central Asian country.

Keywords : autism spectrum disorder, Central Asia, complementary and alternative medicine, cross-cultural perspective, qualitative research

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