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Exploring the barriers and expectations towards health care services among parents/caretakers of people with intellectual disability in Kuantan, Malaysia: A qualitative study

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Abstract

Backgrounds: People with intellectual disabilities (PWID) are often characterized by challenges in learning and difficulties in performing daily activities. These difficulties can have an impact not only on the individuals themselves but also on the people around them, especially their parents, caregivers, and healthcare workers. Therefore, establishing a positive relationship between parents or caregivers and individuals with disabilities is crucial as a key factor in promoting positive healthcare experiences and outcomes. Aim: This study aims to explore the barriers and perceptions toward healthcare services among parents or caretakers of people with intellectual disability, including the challenges and their expectations toward healthcare services. Materials and Methods: This was a qualitative study using purposive sampling. Thirty participants were contacted at the initial stage and invited to participate in the study. Semi-structured in-depth interviews were done among parents and caretakers of PWID who attended Special Care Dentistry and Paediatric Dentistry clinics in Sultan Ahmad Shah Medical Centre, Kuantan, Pahang. Topic guides were generated from literature review and expert opinions, followed by pilot interviews to refine them. However, after the interviews were done for the first 13 participants, we have reached data saturation, and no new themes emerged. The interviews were recorded, verbatim transcribed, and analyzed using Braun and Clarke's guidelines for thematic analysis. Results: The satisfaction of parents or caretakers toward healthcare services for PWID and positive experiences in receiving healthcare services were noted. However, the results revealed several barrier themes in seeking healthcare services: lack of availability of parking, longer waiting time, appointment time, crowded environment, limited information on the availability of the services, and longer travel duration. Furthermore, expectation themes emerged from this study: continuous follow-up, accessibility to healthcare services, and staff attitude. © 2023 Authors

Author Keywords

Barriers; expectations; healthcare; intellectual disability

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