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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

References

- Lee, K, Cascella, M, Marwaha, R.
 (2023) Intellectual disability,
 StatPearls. Treasure Island (FL): StatPearls Publishing
- Alshammari, M, Doody, O, Richardson, I.
 Barriers to the access and use of health information by individuals with intellectual and developmental disability: A review of the literature
 (2018) 2018 IEEE International Conference on Healthcare Informatics (ICHI),
- Oulton, K, Sell, D, Gibson, F.
 Hospitalized children with intellectual disability: Parents as partners in their care (2020) J Appl Res Intell Disabil, 33, pp. 917-926.
- Newman, H, Rudra, S, Burrows, L, Tromans, S, Watkins, L, Triantafyllopoulou, P 'Who cares? A scoping review on intellectual disability, epilepsy and social care' (2023) Seizure Eur J Epilepsy, 107, pp. 35-42.
- Dæhlen, Å, Joshi, SG.
 Immersion as a strategy to facilitate participatory design involving people with

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intellectual disabilities and caretakers as proxies (2019) International Conferences on Advances in Computer-Human Interactions ACHI, pp. 15-24.

- Nirmala, S, Saikrishna, D, Nuvvula, S.
 Dental concerns of children with intellectual disability-A narrative review
 (2018) Dental Oral Craniofacial Res, 4, pp. 2-2.
- Lee, J, Chang, J.
 Oral health issues of young adults with severe intellectual and developmental disabilities and caregiver burdens: A qualitative study
 (2021) BMC Oral Health, 21, pp. 7-8.
- Mahidin, MU.
 (2018) Social Statistics Bulletin Malaysia 2018,
 Department of Statistics Malaysia Official Portal. [Last accessed on March 31, 2023]
- Azmi, N, Mat Basir, S.
 Ratification of the United Nations Convention on the rights of persons with disabilities: Implication and reality from a legal dimension and equality of rights (2020) Kanun: Jurnal Undang-Undang Malaysia, 32, pp. 297-319.
- Campbell, D, Milne, J, Garg, P, Tomsic, G, Ong, N, Silove, N.
 Parents' and service providers' experiences of accessing health services from an intellectual disability health team
 (2021) J Prim Care Commun Health, 12, p. 215013272110140.
- Pelleboer-Gunnink, HA, Van Oorsouw, WM, Van Weeghel, J, Embregts, PJ.
 Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: A systematic review
 (2021) J Intellect Disabil Res, 61, pp. 411-434.
- Appelgren, M, Bahtsevani, C, Persson, K, Borglin, G.
 Nurses' experiences of caring for patients with intellectual developmental disorders: A systematic review using a meta-ethnographic approach (2018) BMC Nursing, 17, p. 1.
- Charles, ML.
 Communication experiences of family caregivers of hospitalized adults with intellectual and developmental disabilities-A qualitative study (2020) Nurs Open, 7, pp. 1725-1734.
- Takebayashi, RB, Fernandes, H, Cruz, MG, Perseguino, MG, Marques, SE, Horta, AL.
 The aging of families with members with intellectual disabilities
 (2019) Rev Bras Enferm, 72, pp. 184-190.
- Abdul, PV.
 Parents having intellectually disabled children: A systematic review of quality of life and mental wellbeing
 (2021) IJIRT, 8, pp. 713-718.
- Mohd, FN, Said, AH, Mat Naji, AS.
 Perceptions toward healthcare and dental care services among parents and caretakers of people with intellectual disability (PWID)-A questionnaire study (2023) J Int Soc Prev Community Dent, 13, pp. 54-61.
- Vergunst, R, Swartz, L, Hem, KG, Eide, AH, Mannan, H, MacLachlan, M
 Access to health care for persons with disabilities in rural South Africa (2017) BMC Health Serv Res, 17, p. 1.

- Sukeri, S, Bakar, RS, Othman, A, Ibrahim, MI.
 Barriers to unmet needs among mothers of children with disabilities in Kelantan,
 Malaysia: A qualitative study
 (2017) J Taibah Univ Med Sci, 12, pp. 424-429.
- Yates, L, Brittleton, L, Beail, N.
 An investigation into the factors which influence attendance rates for psychology appointments in an adult intellectual disability service
 (2022) Adv Mental Health Intell Disabil, 16, pp. 216-225.
- Hashemi, G, Wickenden, M, Bright, T, Kuper, H.
 Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a meta-synthesis of qualitative studies
 (2022) Disabil Rehabil, 44, pp. 1207-1220.
- McQueenie, R, Ellis, DA, McConnachie, A, Wilson, P, Williamson, AE.
 Morbidity, mortality and missed appointments in healthcare: A National Retrospective Data Linkage Study
 (2019) BMC Med, 17, p. 1.
- Fadzil, F, Idris, IB, Kamal Nor, N, Ismail, J, Mohd Tamil, A, Mohamad Noh, K Missed appointments at a child development centre and barriers to access special needs services for children in Klang Valley, Malaysia: A mixed methods study (2021) Int J Environ Res Public Health, 19, p. 325.
- Ahmad, W, Arun, P, Nazli, N, Ratnam, V, Mehta, S, Raina, D.
 Understanding of behavioral problems among young persons with intellectual disability: A self-report
 (2022) J Neurosci Rural Pract, 13, pp. 295-300.
- Smith, J, Baksh, RA, Hassiotis, A, Sheehan, R, Ke, C, Wong, TLB
 PETAL Investigators. Aggressive challenging behavior in adults with intellectual
 disability: An electronic register-based cohort study of clinical outcome and service
 use
 (2022) Eur Psychiatry, 65, p. e74.
- Aguerre, IM, Riley-Powell, AR, Weldon, CT, Pajuelo, M, Celis Nacimento, RA, Puente-Arnao, A
 'Knocking on doors that don't open': Experiences of caregivers of children living with disabilities in Iquitos and Lima, Peru
 (2019) Disabil Rehabil, 41, p. 2538.
- AlShatti, A, AlKandari, D, AlMutairi, H, AlEbrahim, D, AlMutairi, A, AlAnsari, D
 Caregivers' perceptions and experience of caring for persons with Down syndrome in Kuwait: A qualitative study
 (2021) Int J Dev Disabil, 67, pp. 381-390.
- Zdenkowski, N, Lynam, J, Sproule, V, Wall, L, Searston, J, Brown, S.
 Results of a survey of cancer patients willingness to travel to participate in a clinical trial
 (2021) Intern Med J, 49, pp. 1321-1325.
- Grieb, SM, Harris, R, Rosecrans, A, Zook, K, Sherman, SG, Greenbaum, A
 Awareness, perception and utilization of a mobile health clinic by people who use drugs
 (2022) Ann Med, 54, pp. 138-149.
- Shea, B, Bailie, J, Dykgraaf, SH, Fortune, N, Lennox, N, Bailie, R.
 Access to general practice for people with intellectual disability in Australia: A systematic scoping review
 (2022) BMC Prim Care, 23, p. 306.

Whittle, EL, Fisher, KR, Reppermund, S, Lenroot, R, Trollor, J.
 Barriers and enablers to accessing mental health services for people with intellectual disability: A scoping review
 (2018) J Mental Health Res Intell Disabil, 11, pp. 69-102.

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