

The impact on parents of raising a young child with Autism: A phenomenological study of parents

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This study examined the impact on parents of discovering that a child has Autism Spectrum Disorder (ASD) and the challenges of managing the situation. A phenomenological approach was used to investigate parents' lived experiences. Seventeen educated, urban, Zambian, biological parents of children aged 3-7 with ASD were interviewed. In-depth interviews followed Collaizi's phenomenological method as modified by Moustakas (1994). Emerging themes were grouped under ten headings and each was illustrated with quotations from the parents: making sense of the birth of an ASD child; encounters with professionals; parents knowledge and perception of ASD; the search for diagnosis; marital conflict and stress; effects on siblings; costs; cultural beliefs and attitudes in the wider society; inadequate service provision; and parents' hopes and fears and coping strategies. Parents experienced challenges ranging from frustration, pain, confusion, doubt and disempowerment in the pre-diagnostic period, then, at diagnosis, shock, denial and having a feeling like that of losing a normal child through death, followed by some acceptance. Due to shortage of staff, and to bureaucratic, red-tape tendencies in hospitals, the service offered to parents by professionals was inadequate, and sometimes manifested inconsistent opinions and insensitivity. Access to quality remedial services was insufficient. Most schools were unable or unwilling to accommodate ASD children. Marital conflicts emerged which included separations and fighting. Single mothers suffered special challenges, combining study with child caring. Parents incurred significant financial costs for medical attention and transport, and social and emotional costs due to child and parent stigmatization. However, parents developed various coping strategies such as empowerment, humor, openness, faith and belief in God's healing power.

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