



ABSTRACT

Background Disability is a disturbance, or limitation of physical activity involving participation restrictions. Disturbance is a problem in the function of the body and its structure. Restrictions on physical activity are the difficulties faced by individuals in performing tasks or actions while limiting participation is a problem experienced by individuals in engagement in life situations.

Purpose of this study aims to provide an in-depth description of the feelings, explain the obstacles or difficulties experienced and explain the caregiver's expectations of mothers / fathers / brothers in caring for children with disabilities.

Method This study was a qualitative research with descriptive phenomenology approach. Data collection was conducted through in-depth interviews of family caregivers of people with disabilities since birth with inclusion and exclusion criteria. The data were analyzed by Colaizzi's method and data triangulation performed by a coder to maintain data validation. The sample selection was done by purposive sampling. The sample of the study amounted to 17 people who were family caregivers.

Research Results The result of research is that caregiver phenomenon in caring for people with Disabilities since birth is a burden. Psychological burdens such as sadness, disappointment, anger, guilt, depression but ultimately accept. Financial burden, time and stigma.

Conclusion caregiver caring for people with disability since birth is a great burden, that are psychological burden, physical, financial and social burden. There are the psychological burden of anger, disappointment, fear, worry, and guilt which many finally can accept. The physical burden of fatigue, lack of sleep, lack of appetite, resulting in diseases such as gastritis, hypertension, along with muscle and joint disorders. Financial expenses are related to medical expenses, transportation and daily necessities. The social burden of stigma and negative labeling and lack of time together with other families and communities.

Keywords: Persons with Disabilities, Caregiver, Experience



INTISARI

Latar Belakang Disabilitas merupakan suatu gangguan, keterbatasan aktifitas fisik dan pembatasan partisipasi. Gangguan adalah sebuah masalah dalam fungsi dan strukturnya. Pembatasan kegiatan fisik adalah kesulitan yang dihadapi oleh individu dalam melaksanakan tugas atau tindakan. Sedangkan pembatasan partisipasi adalah masalah yang alami individu di situasi kehidupan.

Tujuan Penelitian ini bertujuan untuk memberi gambaran secara mendalam terkait perasaan, hambatan atau kesulitan dan harapan ibu/bapak/saudara dalam merawat anak penyandang disabilitas sejak lahir.

Metode Penelitian ini adalah penelitian kualitatif deskriptif dengan pendekatan fenomenologi. Pengumpulan data dilakukan menggunakan teknik wawancara mendalam (Indepth interview) terhadap caregiver penyandang disabilitas sejak lahir dengan kriteria inklusi dan eksklusi. Proses analisis data menggunakan kerangka Colaizzi 's metode. Pemilihan sampel secara purposive sampling. Sampel berjumlah 17 orang.

Hasil Penelitian Hasil penelitian yaitu bahwa fenomena caregiver dalam merawat penyandang disabilitas sejak lahir adalah merupakan beban. Beban psikologis seperti sedih, kecewa, marah, rasa bersalah, depresi namun akhirnya bisa menerima. Beban finansial, waktu dan stigma.

Kesimpulan Caregiver keluarga yang merawat penyandang disabilitas sejak lahir merupakan beban, yaitu beban psikologis, fisik, Finansial dan sosial. Beban psikologis sesuai teori Kubler-Ross berupa kemarahan, kekecewaan, ketakutan, kekhawatiran, dan rasa bersalah yang akhirnya bisa menerima. Beban fisik berupa kelelahan, kurang tidur, kurang nafsu makan, mengakibatkan penyakit seperti gastritis, hipertensi, disertai dengan gangguan otot dan sendi. Beban finansial terkait biaya pengobatan, transportasi dan kebutuhan sehari-hari. Beban sosial stigma, pelabelan negatif, kurangnya waktu bersama keluarga dan komunitas lain.

Kata Kunci: Penyandang Disabilitas, Caregiver, Fenomena