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Lived experiences of caregivers' caring for their children with congenital heart diseases in Taiwan

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Background: Congenital heart disease (CHD) is the most common type of birth defect that impacts the structure and function of the heart. In Taiwan, the mortality rate of CHD is higher than the rate in the U.S. (Yeh, et al., 2013). Primary caregivers for children with CHD may experience significant emotional impact such as worry toward their care for the children. However, only few studies in the literature that investigated on caregiver's experience of caring for children with CHD at the home setting.

Purpose: The purpose of this study was to understand the primary caregivers' lived experience of caring their children with CHD at the home setting.

Method: This descriptive qualitative study involved semi-structured interviews of 16 primary caregivers of children with CHD. An interview guide was used to guide the interviews. The average age of the caregivers were 39.07 years of age. Colaizzi's (1978) strategy of descriptive phenomenological data analysis were used to extract themes.

Results: Six themes were extracted from the interviews including close observation of children's physical changes, attempt to normalize life of the children, lack of home care resources and knowledge, worry about the impact of CHD on major life events, economic burdens, and needs for social support.

Conclusion: The findings of this study provide insight into the lived experiences of primary caregivers as they care for children with CHD. Healthcare providers are encouraged to provide care knowledge and pertinent resources through innovative strategies to the caregivers who care for children with CHD.

Biography

Dr. Su-Fen Cheng has earned her PhD in 2002 from University of Colorado Health Sciences Center. She used to teaching nursing students since 1994. Currently she has transferred her teaching from nursing department to Graduate Institute of Health Allied Education. She has promoted to full professor in 2016 and served as a director at Graduate Institute of Health Allied Education at National Taipei University of Nursing and Health Sciences in 2017.

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