

探討父母親照顧家中長期重度慢性疾病兒的感受. **An Exploratory Study of the Perception Experiences of Parents Caring for Their Children with Serious Chronic Illness**

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摘要

本研究主要目的在探討父母親養育家中長期重度慢性疾病兒的經驗感受，並比較父母親反應之異同。採質性研究，以半結構式訪談大綱進行訪談，並將內容錄音，共訪談十對父母親。結果顯示父母親照顧家中長期重度慢性疾病兒的經驗過程可歸納為：(1) 疾病方面的感受為：醫療措施、父母重視病兒的程度、未來發展做計劃、擔心病兒的未來、調整性作法；(2) 本身方面的感受為：情緒方面的感受、認知方面的感受、社會方面的感受、父母親本身的心態；(3) 家庭方面的感受為：對配偶的感受、對家中其他小孩方面的感受和經濟因素。父母親反應異同方面，研究結果發現母親擔負大部份的照顧責任。因此，對母親無論在疾病、本身，以及家庭各方面的影響皆大於父親，例如工作、休閒、社交等。另外，因家中經濟因素，母親會在照顧病兒的同時，擔負起家中部份的經濟收入。研究也發現配偶（先生）是母親最主要的支持來源，而先生對病兒的態度，會影響母親養育慢性病兒的態度。大部份父母抱持相同的心態來養育病兒，並盡力提供眾好的照護品質及良好的生長環境。本研究結果可使護理人員對父母親的照顧訊息更為敏感。於提供護理措施時，可評估並協助提供適當的醫療與疾病照顧相關訊息，以提供給病兒一個完整良好的照護品質。

Abstract

The purpose of the present study was to explore and compare the lived experiences of parents caring for their children with serious chronic illness. Ten couples caring for such children participated in the study, which was conducted by a qualitative method. Data were collected through interviews recorded on audio tape following a semi - structured interview guide. The present study showed the lived experience of parents caring for their child with serious chronic illness could be categorized as follows: (1) the perception of illness including medical management, the level of the concern, future planning, worrying about the future, rearrangement. (2) parents' emotional, cognitive and social perceptions. (3) other family-related perceptions including the perceptions of spouse, other children and economic situation. The results revealed that in most of the cases, the mothers took the major role in caring. Many of them were unemployed, and had less leisure time and less social life. For economic reasons, most of the mothers had to share the family income burden in addition to caring for the child. The results also showed that father was the most

supportive source for the mother. Furthermore, the attitude of the mothers to care for the sick child was significantly by attitude of the fathers. The results revealed that the majority of the parents had similar attitudes of wishing to provide the best quality of care and living environment for their child with serious chronic illness. These results provide informative knowledge intrinsic to the parents' perceptions in caring for their chronically in child. We suggest that equipping public health nurses with such information will improve the quality of home care for these sick children and provide better support for their parents.