

長期依賴呼吸器病童之家庭福利需求研究~兼論福利資源之使用

A Research of the Family Welfare Demand for Long-Term Respirator Dependant Child

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摘要

國內目前很少有針對長期依賴呼吸器病童之家庭福利需求研究。因此，本研究嘗試以實證調查方式與探索性的研究，試著發現長期依賴呼吸器病童之家庭現有問題、家庭福利需求、需求實際使用情形，以提供給政策規劃相關單位及社會福利機構，作為家庭服務提供之參考。

本研究主要以加入兒童長期呼吸照護聯盟之醫院，長期依賴呼吸器病童之家屬為抽樣對象。研究範圍以八家兒童長期呼吸器依賴的醫院及居家呼吸器使用個案，以親自訪談的方式進行問卷調查，藉此提高研究的信度及效度。共得到個案數 110 人，有效回收問卷數 105 份。運用社會科學統計套裝軟體（SPSS for window 11.0）進行資料處理與分析。

研究結果如下：在長期依賴呼吸器病童之家庭現有問題中，以「社會參與問題」最多。在家庭需求中，以「資訊性需求」最多。在需求實際使用中，以「家庭經濟需求使用」為最多。長期依賴呼吸器病童狀況對家庭現有問題、家庭福利需求有所影響；但對需求實際使用呈現出沒有差異。長期依賴呼吸器病童家庭狀況對家庭現有問題、家庭福利需求和需求實際使用均有不同程度的影響。長期依賴呼吸器病童家庭現有問題與家庭福利需求、家庭現有問題與需求實際使用的題項上呈現正相關。家庭現有問題複雜性高，不易用來預測家庭福利需求及需求實際使用。

研究建議：（以下從生態系統來建構病童家庭策略）

（一）微視系統：1.病童在幼兒期受到微視系統影響最多，特別是與父母親的互動，故親職教育相當重要。學校可安排專任輔導老師或社工人員、義工協助家庭，學習如何與孩子相處，可紓緩父母或主要照顧者的長期負荷與緊張壓力。2.提供服務之單位為減低經濟條件較差之家庭負擔，在基本收費原則下，可訂定彈性收費標準，應依照每個家庭個別差異收取費用。

（二）中間系統：1.在政策上可擬定彈性的工作方式，讓父母可以彈性運用時間，兼顧工作與照顧病童。2.居家照護訓練：應多舉辦照顧長期依賴呼吸器病童之照顧訓練課程，尤其在病童剛使用呼吸器半年內應主動給予協助。若家中其他成員均能夠清楚了解該如何照顧病童，必然可以分擔主要照顧者之壓力。

（三）外部系統：1.提供短期或臨時托育照顧服務：提供具備合格的醫療人員，在醫院、社區之間或附近，成立臨托中心或提供在宅服務，提供父母短期或臨時照顧服務，亦可達喘息服務及協助家庭休閒，解除壓力之功能。2.提供家庭支持

並成立病友互助網絡：鼓勵家長參加病友支持團體，家長們彼此經驗分享，讓父母有機會外出接受自我成長與教育課程。3.醫務社工主動探視：在社會福利機構中扮演補充性及支持性的角色，利用個案管理的方式，提供長期依賴呼吸器病童之家庭服務。

(四) 巨視系統：1.主動提供申請補助之相關資訊，讓病童家庭可以清楚地了解本身所該享有哪些福利？該去哪裡申請？而非讓知道表達者得到福利，不知如何求助者喪失應得的權利。2.提供失業或月收入較低家庭的照顧需求，主動撥款提供服務相關醫療單位降低收費標準，或以專案募款的方式，為這些經濟較為困難的家庭籌措醫療照顧基金，直接提供給服務單位協助長期依賴呼吸器的家庭照顧病童之用。3.建立完善的通報機制，在有長期依賴呼吸器病童家庭進入通報系統後，政府或相關醫療、社會服務機構都應該主動提出各種服務，而非被動的等待家庭來請求援助。

Abstract

The welfare of long-term respirator dependant child (LTRDC) family is becoming more and more demanded, but it is hard to find any research paper concerning this aspect in Taiwan. Therefore, the researcher attempts to investigate the existence problems in LTRDC family, the welfare demand of LTRDC family and the welfare actual requested by the LTRDC family. The conclusion of this research will be provided to government and relevant organizations for reference.

The investigation cases of LTRDC family mainly got from the member hospitals of CRC and some from home care LTRDC family. Since LTRDC cases are not quite command in Taiwan, it is not easy to have many samples for research. Therefore, personal interview with every person who actually cares LTRDC in family was taken in order to get study cases as many as possible. Totally 110 cases including 5 invalid cases were got in interview. In order to analyze data from investigation, the social science statistic software SPSS for window version 11.0 was used as analysis tool. The result of analysis was as follows. For frequencies and percentage analysis, in the analysis of existence problem in LTRDC family, "social participant problem" dominate. "information need" is main demand of family welfare need. And, actual welfare request mostly is "Financial request". In significant analysis, "LTRDC sickness" to "financial problem", "family structure" to "financial problem" and "family structure" to "leisure and care request" present more significant variance. From stepwise regress analysis, though there are significant correlation exist between family existence problem and family welfare need, and between family existence problem and welfare actual requested, but owing to weakness determination (small R square) it is not suitable to predict family welfare need and welfare actual requested by family existence problem.

After data analysis, suggestion from researcher was stated here. (Base on Ecological system theory)

From micro-system point of view:

1. LTRDC is strongly influenced by micro-system especially by interaction with their parents. Therefore, training for how to take care of LTRDC plays an important role. In this consideration, social worker may be arranged to assist parents for getting along with their children and for relieve their pressure.
2. In order to serve the family with low income, flexible service charge should be considered according to each family's situation by welfare organization through the government's support.

From meso-system point of view:

1. Government should provide LTRDC family to have part time job easily, then parents can both make living and take care of LTRDC.
2. Provide LTRDC family home attendance training, especially LTRDC using respirator within half a year. If other members in family know how to take care of LTRDC, the pressure of parents could be relieved.

From exo-system point of view:

1. Establish long-term and temporary care center to provide long-term and temporary service for LTRDC family. It also could facilitate family enjoy their free time.
2. Encourage parents to take part in support group. They could share their experience in support group. Also, provide LTRDC parents the opportunity to participate self-growth course.
3. Welfare organization should play the supplement and support role. Provide service to LTRDC family by using Case Management method.

From macro-system point of view:

1. Enthusiastically provide related information concerning how to reach welfare, which makes the LTRDC family understand their right and know how to apply welfare.
2. Provide funds to medical care unit initiatively through government and public donation, to lower down service charge for LTRDC family with unemployment or low income.
3. Establish integrated notification system. Combine notification system and Family service program to provide LTRDC family initiatively.