

The Stress and Needs of Primary Caregivers of Children Depending on Oxygen Therapy in Taiwan: A Questionnaire Survey

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Background

- Advances in medical and nursing technology have led to decreased mortality and increased morbidity among many populations, including children.
- In Taiwan, according to Chronic Respiratory Care Association, in a sample of 90 ventilator-dependent children, the top three diseases amongst these children refer to central nervous system (37.5%), enterovirus (23.75%) and muscular dystrophy (12.5%).

The Gap

- LCBH Association in Taiwan makes an estimation that there are nearly hundred children each year depending on long-term ventilator at home.
- There is a group of children at home who are depending on prolonged oxygen therapy, and their primary caregivers' stress and needs have not been studied, and therefore their needs have not been met or made clear to the health care professionals and policy makers for evidence-based interventions.

The Study

- This was a cross-sectional study with questionnaires.
- The subject recruitment was a purposive sampling from a pediatric OPD in one teaching hospital in Taipei from which the ethics approval had been gained.
- Health Care Financial Administration, HCFA in US defines prolonged mechanical ventilation, PMV as patients use oxygen over 6 hours per day and continue over 21 days.

Inclusion Criteria

- Caring for a child depending on oxygen ≥ 6 hours per day and continue over 21 days;
- Primary caregivers (primary or secondary) can be parents, grandparents or any adult relatives caring for the oxygen-dependent child at home; &
- Primary caregivers: age ≥ 18 years old and able to consent to fill out the surveys.

Questionnaires

- Demographic data included two parts: (1) individual background of the primary caregivers and (2) the oxygen-dependent child's background data.
- The questionnaire, "The Survey of the Stress of the Family of An Oxygen-Dependent Child" includes three dimensions: (1) stress in the child's physical symptoms; (2) stress in the disrupted family functioning; & (3) stress in the self.
- There were 59 questions in total with a likert scale from 0-5.
- The questionnaire: CVI = 4.87; Cronbach's alpha = 0.975.

Data Analysis

- SPSS 19.0 for Window
- Generalized Linear Model (GEE) was used: one or two caregivers in a family were involved and both caregivers were related to each other.
- Working correlation matrix was adopted: one particular family could only have two caregivers in maximum.
- Regression coefficient: Robust standard error.
- GEE: Univariate analysis and Multivariable analysis

Demographic data of 104 subjects

- A total of 76 families (48 families with 1 caregiver; 28 families with 2 caregivers)
- 12 families: father as the only caregiver
- Female caregivers = 70; Male caregivers = 34
- Mean age of caregivers = 39.7 years old (SD = 8.93)
- Educational background: high school (44%)
- Income per monthly: \$20,000-\$39,999 NT equivalent to \$666 - \$1333.3 USD
- Health status: good (45%); poor (42%)

Demographic data of oxygen-dependent child

- There were 76 oxygen-dependent child.
- Girl = 31 (41%); Boy = 45 (59%)
- Average age of the child = 6.68 (SD = 5.15)
- Diagnosis: respiratory diseases 71 (68.3%); cardiac diseases 11 (11%); congenital diseases 24 (32%); Enterovirus 13 (13%); Seizure 27 (26%)
- Consciousness: yes = 66 (87%); no = 13 (17%)
- Use of oxygen per day: Mean = 11.39 hours (SD = 6.21)

Stress of caregivers of an OD child

- “The Survey of Stress of Family of OD Patients” consists of three dimensions of stress, and the sequence of stress level from highest to the lowest by the subjects were:
 - 1) stress in the disrupted family functioning: Mean = 4.02; SD = 0.85
 - 2) stress in the child’s physical symptoms: Mean = 3.61; SD = 0.67
 - 3) stress in self: Mean = 3.38; SD = 0.67
- Total score for the stress as a whole: Mean = 3.57; SD= 0.62; caregivers scored a moderately high level of stress when caring for an oxygen-dependent child at home.

GEE: Stress in the child's physical symptoms

Univariate Analysis: (higher level of stress groups)

1. monthly income > \$40,000 NT ($B = 0.31, p = 0.037$)
2. use of oxygen > 10 hrs/day ($B = 0.31, p = 0.002$)
3. child's age (preschoolers & teenager) ($B = 0.53, p = 0.007; B = 0.47, p = 0.03$)

Multivariable Analysis: (higher level of stress groups)

1. monthly income > \$40,000 NT ($B = 0.39, p = 0.006$)
2. child's age (preschoolers & teenager) ($B = 0.50, p = 0.001; B = 0.56, p = 0.06$)
3. educational background < high school ($B = -0.32, p = 0.016$)
4. self perceived health status: poor ($B = 0.25, p = 0.018$)

GEE: Stress in the disrupted family functioning

Univariate Analysis: (higher level of stress groups)

1. Marriage status: Married < Single ($B = -0.45, p = 0.008$)
2. The child's gender: Boy > Girl ($B = 0.46, p = 0.015$)
3. The child's age: preschoolers ($B = 0.48, p = 0.031$)
4. Cost of living: high ($B = 0.01, p = 0.007$)

Multivariable Analysis: (higher level of stress groups)

1. . The child's gender: Boy > Girl ($B = 0.42, p = 0.022$)
2. child's age: preschoolers ($B = 0.49, p = 0.03$)
3. self perceived health status: poor ($B = 0.33, p = 0.014$)

GEE: Stress in Self

Univariate Analysis: (higher level of stress groups)

1. Marriage status: Married < Single ($B = -0.26, p = 0.014$)
2. The child's gender: Boy > Girl ($B = 0.30, p = 0.032$)
3. Use of oxygen > 10 hours per day ($B = 0.46, p = 0.001$)
4. Cost of living: high ($B = 0.02, p = 0.001$)
5. Self perceived health status: poor ($B = 0.27, p = 0.029$)

Multivariable Analysis: (higher level of stress groups)

1. The child's gender: Boy > Girl ($B = 0.28, p = 0.02$)
2. Use of oxygen > 10 hours per day ($B = 0.34, p = 0.005$)
3. Cost of living: high ($B = 0.02, p = 0.001$)
4. child's age: preschoolers ($B = 0.28, p = 0.042$)

GEE: Stress as a whole

Univariate Analysis & Multivariable Analysis:

(higher level of stress groups)

1. The child's gender: Boy > Girl ($B = 0.30, p = 0.023$; $B = 0.29, p = 0.015$)
2. child's age: preschoolers ($B = 0.43, p = 0.012$; $B = 0.39, p = 0.004$)
3. Use of oxygen > 10 hours per day ($B = 0.37, p = 0.004$; $B = 0.25, p = 0.03$)
4. Self perceived health status: poor ($B = 0.25, p = 0.021$; $B = 0.26, p = 0.01$)
5. Cost of living: high ($B = 0.02, p = 0.001$; $B = 0.01, p = 0.003$)

Discussion: Prediction in the stress of primary caregivers of oxygen-dependent child

Factors in the caregivers themselves:

1. Self perceived health status
2. Family economic status
3. High risk families including single parent; low economic status; both parents are working

Factors in the OD children:

1. Age groups eg. Infancy and preschooler groups
2. Gender (Boy in Chinese Families)
3. Highly depending on oxygen therapy

Conclusion

1. The primary caregivers felt stressful when caring for an oxygen-dependent child at home, particularly when confronting with their family dynamics and functioning were being disturbed and required great readjustment.
2. The primary caregivers also expressed stress when caring for the oxygen-dependent child who required great attention to their developmental care particularly during infancy, preschooler and teenage ages.

Recommendations

1. Support to sustain and strengthen the function of family dynamics and activities should tailor to the high risk family groups such as single-parent, low economic status, families with young and teenage children and families with children depending on long hours of oxygen therapy at home.
2. Financial and respite supports are particularly helpful for the high risk family groups.
3. Provision of appropriate developmental needs and care for the OD child is also important.

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Thank you
for your attention & suggestions!

