Relationship between Families Perception of Health and Support in the Care of Vulnerable Children

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Abstract

Introduction: The role of family support in the care of vulnerable children is rarely discussed, yet has a major impact on family health. How family members’ perceptions of their own health affect their vulnerable children has not been previously explored.

Purpose: The objectives of the study were to assess and compare the health status of perception using the Duke Health Profile (DUKE) and perceptions family support using the family APGAR (FAPGAR) across groups-families of children with muscular dystrophy, attention deficit hyperactivity disorders (ADHD), and chromosomal abnormality (Turner syndrome or Klinefelter syndrome, TS/KS).

Methods: The participants of the study were 286 from three cross-sectional studies from a southern medical hospital in Taiwan.

Results: This manuscript investigated the relationship between families’ perception of health and support in the care of vulnerable children with DMD/SMA, ADHD, or TS/KS. By using multiple comparison, correlation and regression analysis, the authors reported that Duke Health Profile was significantly correlated with family support. Additionally, social health, age, marital status, and vulnerable status as predictors accounted for 35.3% of the variance in family support.

Discussion: Data suggest the efficacy to care for families of children as show in the DMD/SMA group, compared to ADHD and chromosome abnormality groups. The authors indicate that family support is critical in the care of vulnerable children. This study did provide some new information in the related field.

Keywords: Family health promotion; Family health; Family nursing; ADHD; DMD; SMA

Introduction

Families’ perception of health and support is important to make positive functional resources in the care of vulnerable children. Vulnerable children in this study included the disabled children with Duchenne muscular dystrophy (DMD)/spinal muscular atrophy (SMA), attention deficit hyperactivity disorder (ADHD), or chromosomal abnormality (Turner syndrome or Klinefelter syndrome, TS/KS). DMD/SMA is a primary genetic chronic disorder of motor and lung function and scoliosis by early muscle weakness that can lead to difficulties with walking, respiratory complications, and impact independence in daily activities [1,2]. ADHD is significant problems with attention and inhibitory control that cause attention deficits, hyperactivity, or impulsiveness with academic difficulties as problems in relationship with family members [3]. TS/KS, a chromosome structure is altered and govern physical and medical characteristics, such as susceptibility to lymphedema, osteoporosis and fractures, structural malformations of the kidney, autoimmune thyroiditis, diabetes mellitus, inflammatory bowel disease [4-6], or higher risks for scoliosis, lordosis, and kyphosis [7].

The vulnerable situations have been found to exhibit relatively enduring health behavior, health values, family support, and health perceptions of families that can be developed and performed [8,9], and situations of disability/worse health problem can compromise the independence and functional capacity of the vulnerable children thus making them dependent on caregivers, and inducing functional impairment in family, social, and academic settings that was similar in these groups of children and caused problems regarding families’ health issues and general dysfunctional family support [10-14].

These untreated health problems may lead to major complications or complex limitations in activity and participation family time [4,15-18]. Policy programs for the vulnerable population were created and changed as generation change how that influenced families perception of their health and family support. However, empirical evidence to guide health professional collaborate with families to provide family health promotion intervention. Especially, disturbances...
in family function were related to a high risk of family depression [8,10,12]. Studies with parents of children with TS with depressive were associated with a poorer physical health and related to quality of life score (HRQoL) [12,19]. Family of children with ADHD also found higher conflict when compared with families of children without psychological illness [20]. Studies with family of children with ADHD found that anxiety was directly affecting caregiver health [13], family support was directly affecting caregiver health in family of children with ADHD or DMD [21,22]. Family support may be a critical early contribution to the risk of psycho-social pathology [23], but it is not recognized whether specific traits of family support may diversely contribute to different vulnerable types. More complex relationships between these variables have not been investigated.

Family support is implicated in families' satisfaction, receptiveness, responsiveness, and ability to take care of their children's needs. It also offered support to the family within a family unit for the care of a member with disabilities, as measured by constructs of the Family APGAR (FAPGAR), including adaptation, partnership, growth, affection, and resolve [24]. This study translated the FAPGAR into English means family caring index to measure of family members' satisfaction with the five aspects of family life. The role of these factors in the care of vulnerable children is rarely discussed, and no studies have explored aspects of family support in groups of children with vulnerable situations. The effect of family members' perceptions of their own health and family support on their own vulnerable children has received little examination in outpatient care settings.

Purpose
The aims of the study were to:
• assess families’ perception of health associated with their children in different vulnerable care settings
• re-examine comparisons of families’ perceptions of their own health and family support with a defined sample of vulnerable children in different vulnerable care settings
• explore the relative contribution of subscales of health variables and demographic variables correlated with caregivers/family members' family support in the care of vulnerable children.

Methods
Design
This study was a cross-sectional with self-report questionnaire analysis in the families of vulnerable children. The study was approved by the Institute Research board of KMUH (No.:2014058). All participants were volunteers and their anonymity was strictly maintained. The sample was a convenience sample that was referred by the hospitals’ physicians or institute's social workers. The investigators informed the interviewees of the procedures, obtained their informed consent, and asked them complete the questionnaires after the caregivers agreed to participate in a family health promotion model survey. Completed questionnaires were returned to the research team using a prepaid envelope. A total of participants in 286 families including parents, caregivers, siblings, or even patients (over 20 years) were collected in outpatient clinics of pediatric and pediatric psychiatric in one hospital and one institute of muscular dystrophy association. Two major measurements addressed individual health status and family members’ perceptions for satisfaction of their family support by the Duke Health Profile and the FAPGAR, and demographic questions for families with a DMD/SMA, ADHD, or TS/KS. Researchers would like to examine the gap of health and family support among above three groups and past periods to find the similar factors.

Sample
No missing data regarding both of the above mentioned measures (DUKE and FAPGAR) were included in the present study. The sample ranged in age from 20 to 64 years (mean=41.47 years, SD=8.83). The representative sample consisted of 42 families of children with DMD (n=55, mean age=42.07, SD=10.78), 44 families of children with SMA (n=58, mean age=43.33, SD=9.66), 96 families of children with ADHD (n=109, mean age=40.46, SD=6.27), and 43 families of children with TS/KS (n=64, mean age=41.06, SD=9.74). Total of 225 families were from parents (n=242, 84.6%), sibling (n=2, 0.7%), patients (n=32, 11.2%), and caregivers (n=10, 3.5%).

Measures
Independent variables
Differences were examined regarding vulnerable status, age, education, family monthly income, marital status (married, separated, divorce, single), living location (rural, town, urban, suburban), family structure (nuclear, expended, single, other), and power of decision (direct, indirect, silence, other). Means and standard deviations for families’ general health and family support (including subscales) and t/F values are presented.
Table 1: Comparison of reliability analysis of the Duke Health Profile between the current study and original.

Duke Health Profile

The measure is a survey constructed by Parkerson [25], 17-item instrument contains five positive functional health measures (physical, mental, social, self-esteem, and perceived health) and five negative functional health measures (pain, disability, anxiety, depression, and anxiety-depression). It used simple 3-response-options multi-item mean scores transformed to 0-2 to 0 to 100, for example 2=“yes, describes me exactly”, 1=“describes me somewhat”, or 0=“no, does not describe me at all”. Others were reported in the extent of difficulty experienced in an area “0=a lot, 1=some, or 2=none”, or reported in terms of frequency during a one week “2=a lot, 1=sometimes, 0=none; or 2=none, 1=1-4 days, 0=5-7 days’. Higher scores on positive functional health indicated better health, and higher scores on negative functional health indicated worse health.

Table 1 showed the internal consistency reliability results of the subscales (0.53-0.71) of the Duke Health Profile overall (0.80) for this study and compared them with those reported by Parkerson et al. [26] and Beaton et al. [27].
Table 2: Aggregated families demographics by clinics and setting for the entire study period (N=286).

Table 2 presents the characteristics of the participants and their family. Participants were female (66.1%; N=169), married (76.8%, N=220), over two thirds had completed education over 12 years, whose monthly income was over 30000, and primary living at urban or town.

| Subscale         | Research 1 (N=113) | Research 2 (N=109) | Research 3 (N=64) | ANOVA F/p | Post hoc test Results/MD, p(LSD) |
|------------------|---------------------|--------------------|-------------------|-----------|---------------------------------|
| Physical health  | 56.90/22.24         | 64.50/19.36        | 70.00/18.73       | 8.57/0.00 | B>A/7.59, <0.01                  |
|                   | M/SD                | M/SD               | M/SD              |           |                                 |
| Mental health    | 61.50/18.62         | 64.95/22.26        | 72.90/20.68       | 6.09/0.01 | C>B/7.70, 0.02                   |
|                   | M/SD                | M/SD               | M/SD              |           |                                 |
| Social health    | 65.75/20.12         | 66.15/18.80        | 72.26/18.85       | 2.88/0.06 | C>B/6.35, 0.04                   |
|                   | M/SD                | M/SD               | M/SD              |           |                                 |
| Self-esteem      | 67.43/18.07         | 69.08/18.18        | 75.00/19.31       | 3.42/0.03 | C>B/5.76, 0.05                   |

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Perceived health 59.29/36.32 69.27/34.63 73.39/29.64 4.16/0.02 B>A/9.97, 0.03
Pain 45.58/30.29 40.83/30.55 35.48/26.22 1.91/0.15
Disability 13.27/28.36 9.63/23.05 5.61/20.46 2.07/0.13
Anxiety 37.24/17.15 34.86/20.98 30.78/18.45 2.31/0.10
Depression 40.71/18.45 37.98/21.15 31.61/18.92 3.62/0.03 A>C/6.38, 0.01
Anxiety-depression 38.81/17.42 36.89/21.15 30.76/19.17 2.31/0.10
Duke Health Profile 62.75/15.04 66.67/14.77 73.15/15.42 9.65/0.01 C>A/10.27, <0.01

Table 3: Subscales of the Duke health profile by clinics and setting for the total study.

Dependent variable
Family APGAR. The FAPGAR contained five items to measure five dimensions, adaptability, partnership, growth, affective, and resolve, using a 3-point Likert scale ranged from 0-hardly ever, 1-some of time, to 2-almost always [24,28]. Scores ranged from 0-10, with a higher score indicating greater satisfaction with family support. The Cronbach's alpha (0.88) indicated feasibility to be used in clinical settings.

Data analysis
Data analyses were performed using SPSS 21. Descriptive statistics were used to examine families' perception of health and family support in children with different diseases. Multiple Comparison analyses among three clinical or institute settings were examined using ANOVA. Pearson correlations were utilized to analyze relationship among health and family support variables and demographic variables. Contributing predictors were analyzed utilizing multiple regressions.

Results
Table 2 presents the characteristics of the participants and their family. Participants were female (66.1%; N=169), married (76.8%, N=220), over two thirds had completed education over 12 years, whose monthly income was over 30000, and primary living at urban or town. Approximately three quarters of family structure were nuclear and directly power to propose idea or plan (76%). There were no significant differences in characteristics in age, resilience location, and family structure among three groups. Table 2 also presented significant differences in education, family monthly income, marital status, and power decision between the three groups of vulnerable children.

Table 3 shows significant differences between clinics/setting are noted for the all subscales of all positive functional health and the higher scores reported negative functional health fell into family pain category for the ADHD and the TS/KS group. The higher scores reported positive functional health fell into the family self-esteem for DMD/SMA or TS/KS. Different presented with ADHD depicting the higher scores fell into the family perceived health. Among the participants, based on mean differences TS/KS had higher scores self-esteem, social health, and mental health than ADHD group or DMD/SMA group. ADHD group had higher scores physical health and perceived health than the DMD/SMA group, but that were lower scores than TS/KS. DMD/SMA group had higher scores anxiety, depression, and anxiety-depression than TS/KS group, ADHD group had a higher score anxiety-depression than TS/KS group. TS/KS group had a higher score overall Duke Health score than DMD/SMA or ADHD group (Table 3).

Table 4 presents all participants' self-esteem received the highest score and the second highest score was social health. Significant differences among the three study period/different samples are found for the subscales of physical health, perceived health, and overall score (Table 4). Compared to literature in 2007 for DMD group, it expressed significantly greater to increase physical health and overall Duke Health scores, but no significant differences among the three study periods/ different samples for all subscales of negative functional health (Table 4).
Among the components of FAPGAR in this study, resolve received the highest score, and adaptation received the second highest score. The other components are listed in descending order of score, i.e., affection, growth, and partnership. Table 5 shows the overall scores of family support and their subscales at different settings/clinics for families of children with different types of diseases. Significant differences in family support score, subscale of adaptation, and partnership score are found between setting/clinics. The mean differences from highest to lowest were in partnership and in adaptation among three types of vulnerable groups. However, compared to literature in 2007 DMD group or the TS/KS group had lower adaptation than the DMD/SMA group (Table 5).

### Table 4: Subscales of the Duke health profile by authors for the total sample.

| Subscale                  | Setting A: Chen & Clark, 2007 DMD | Setting B: DMD/SMA, ADHD 2012 | Setting C: DMD group at 2007 |
|---------------------------|-----------------------------------|--------------------------------|-------------------------------|
| Physical                  | 62.62/20.94                       | 56.90/22.24                    | 66.11/19.51                   |
| Mental health             | 64.97/20.07                       | 61.50/18.62                    | 64.13/19.73                   |
| Social health             | 67.41/20.07                       | 65.75/20.12                    | 65.16/21.23                   |
| Self-esteem               | 69.72/18.56                       | 67.43/18.07                    | 71.51/21.51                   |
| Perceived health          | 66.26/34.64                       | 59.29/36.32                    | 78.17/34.93                   |
| Pain                      | 41.78/29.81                       | 45.58/30.29                    | 43.25/26.35                   |
| Disability                | 10.14/20.07                       | 13.27/28.36                    | 7.94/19.40                    |
| Anxiety                   | 35.20/18.24                       | 37.24/17.15                    | 33.93/19.53                   |
| Depression                | 38.01/19.80                       | 40.71/18.45                    | 37.62/20.33                   |
| Anxiety-depression        | 36.54/18.86                       | 38.81/17.42                    | 35.37/18.75                   |

A: DMD/ADHD, and chromosome abnormality group  
B: DMD/ADHD group at 2012  
C: DMD group at 2007  

| Research A | Setting A: Chen & Clark, 2007 DMD | Setting B: DMD/SMA, ADHD 2012 | Setting C: DMD group at 2007 | ANOVA | Post hoc test |
|------------|-----------------------------------|--------------------------------|-------------------------------|-------|--------------|
|            | M/SD                              | M/SD                           | M/SD                          |       | p            |
| N=286      | N=126                             | N=113                          | N=109                         |       |              |
| Adaptability| 1.34/0.68                         | 1.25/0.71                      | 1.48/0.66                     | 1.27/0.68 | 1.42/0.64 | 3.12/0.03 | 2>1/.23, 0.01 |
| Partnership| 1.26/0.72                         | 1.21/0.74                      | 1.37/0.70                     | 1.14/0.71 | 1.41/0.66 | 3.16/0.03 | 2>3/.23, 0.01 |
| Growth     | 1.29/0.68                         | 1.33/0.69                      | 1.36/0.60                     | 1.17/0.66 | 1.28/0.66 | 1.62/0.19 | 4>3/3.26, 0.02 |
| Affection  | 1.32/0.63                         | 1.29/0.63                      | 1.37/0.60                     | 1.23/0.63 | 1.40/0.64 | 1.50/0.22 | 4>3/3.26, 0.02 |
| Resolve    | 1.59/0.57                         | 1.56/0.64                      | 1.61/0.57                     | 1.53/0.55 | 1.72/0.45 | 1.59/0.19 | 4>3/3.90, 0.03 |
| Overall family support | 6.80/2.72                         | 6.63/2.85                      | 7.19/2.72                     | 6.34/2.60 | 7.23/2.72 | 2.57/0.05 | 2>3/.86, 0.02 |

1: DMD group at 2007
positively related to physical and perceived health (r=0.17-0.21; p=0.01). Family structure was positively related to mental and social health, and self-esteem (r=0.12-0.15; p=0.01-0.04); however, it was negatively related to disability, anxiety, depression, and anxiety-depression (r=-0.18 to -0.25; p=0.01).

For identified factors of overall health or subscales of health associated with family support before determining the contributing predictors of family support, we found that total scores of family support, including subscales, were significantly positive for subscales of positive functional health (r=0.24 to 0.50, p=0.001), and significantly negative correlated with family support for subscales of negative functional health (r=-0.15 to -0.40, p=0.001-0.013), and exhibited higher positive correlation for overall health (r=0.49, p=0.001). In addition, there were no significant correlations found between marital status (r=0.12, p=0.51), resilience locations (r=-0.04, p=0.95), and family structure (r=0.09, p=0.15) with family support. But gender (r=0.161, p=0.006) and monthly income (r=0.127, p=0.031) exhibited significantly correlation with family support.

Regressions
Hierarchical multiple regressions were performed to determine the relative contribution of subscales of health variables correlated with caregivers/family members’ family support (Table 6).

Table 5: Total Family Apgar compared by clinics/authors.

| No. | Model      | B     | SE   | β    | CL (lower-bound) | CL (upper-bound) | t (p) | R   | R^2  | ΔR^2 | F      |
|-----|------------|-------|------|------|-----------------|-----------------|-------|-----|------|------|--------|
| 1   | Constant   | 1.073 | 0.593| -0.095| 2.24            | 1.808 (0.072)   | 0.542 | 0.249| 0.282| 23.353^*|
|     | Mental health | 0.024 | 0.01 | 0.188 | 0.005           | 0.043           | 2.462 (0.004) |
|     | Social health | 0.038 | 0.012 | 0.28 | 0.015           | 0.061           | 3.271 (0.001) |
| 2   | Constant   | 3.65  | 2.254| -0.787| 8.086           | 1.620 (0.106)   | 0.553 | 0.305| 0.28 | 12.094^*|
|     | Social health | 0.039 | 0.013 | 0.286 | 0.014           | 0.065           | 3.038 (0.003) |
| 3   | Constant   | 1.236 | 2.318| -3.328| 5.8             | 0.533 (0.594)   | 0.594 | 0.353| 0.312| 8.593^*|
|     | Social health | 0.04  | 0.013 | 0.291 | 0.015           | 0.065           | 3.108 (0.002) |
|     | Age        | -0.694| 0.308| -0.13 | -1.301          | -0.087          | -2.250 (0.025) |
|     | Marital status | 0.937 | 0.388 | 0.149 | 0.174           | 1.7             | 2.418 (0.016) |
|     | Vulnerable status | 0.101 | 0.031 | 0.175 | 0.04            | 0.162           | 3.257 (0.001) |

^*p<0.001

Table 6: Results of final model of family health and demographic variables on family support.

In step 1, family support was the dependent variable and all positive functional healthy variables were the independent variables, and were entered into the regression. Result showed that the positive functional healthy variables including mental health and social health (β=0.19 and 0.28; p=0.01) accounted for 29% of the family support variance. In step 2, all negative functional health variables were added to the equation, only social health contributed significantly to the regression equation (β=0.29, p=0.01). In step 3, demographic variables (age, vulnerable status, family monthly income, occupation, marital status, family structure, and family development) were added to the equation, four variables including social health and demographic variables (age, vulnerable status, and marital status) accounted for 35.3% of the family support variance. Adjusted variance attributable to these variables was 0.312, which was significantly different from zero, F17, 268=8.593, p=0.001.
Discussion

The paper explored the measurement properties of scales used to measure participants' health and family support in southern Taiwan. The results of this study indicated that the Duke Health Profile and the Family APGAR constituted self-reported scales with available psychometric properties exhibiting internal consistency. Individuals in the three groups perceived lower scores in the subscales of mental health, social health, self-esteem, and overall health than the TS/KS group. Moreover, physical and perceived health received lower scores in the DMD/SMA group compared with the ADHD or the TS/KS group. In contrast to the families' perception of health noted in the literature, the DMD group reported higher scores in physical health, perceived health, and overall health [29] than the DMD/SMA group in 2012, which received higher scores in the above three groups of this study. And was also higher than the DMD/SMA or the ADHD group, and that reported in previous studies in 1999 [26] and 1997 [27], except for physical health. In addition, received self-esteem the highest score and social health received the second highest score, which was the same as that of the DMD/SMA group's families in 2012. In 2007, parents of children with DMD received the highest perceived health score, and received self-esteem the second highest score among subscales of the Duke [29]. Similar results comparing three study periods/different samples were found on subscales of negative functional health. It may support parents of children with disabilities have stress that may link to child behavior disturbances, limitations in child function, and families demands [30].

The reason for the self-reported lower scores of subscales of positive functional health for all participants and higher scores were reported (indicating worse health status) in anxiety, depression, and anxiety-depression in the DMD/SMA group than the TS/KS group. It is associated with medical technique and health delivery systems that have improved to the lifespan of children with muscular dystrophy [22,31]. This is because as children's ages increase and there is a gradual increased immobility and transportation limitations, and ultimately death, all of which combine to produce physical and mental overload for families the care of children with muscular dystrophy increasingly depends on families to take care of their worsening condition [6,22,32]. Therefore, overload causes families to report lower scores (worse health) in all positive functional health variables in the DMD/SMA group than the ADHD or the TS/KS group. In addition, higher score of anxiety-depression indicated worse health in the ADHD group than the TS/KS group. This result was similar to Cussen [33] and Theule et al. [34] who found that parents of children with ADHD had more parental depression, anxiety, and higher stress levels that were a result of their child's ADHD symptoms. However, there were no significant differences in reporting subscales' scores of negative functional health in different study periods.

Knussen and Sloper [35] reported that parenting stress of children with disability was influenced by social support, marital satisfaction, and financial resources. Murphy et al. [36] recommended that parental stress of children with epilepsy went up as the child's physical, social, school, and emotional function increases not related to a child's disability itself but to other parent, family, and social factors. However, our findings showed that marital status was not associated with depression, anxiety, and family support, which is inconsistent with previous studies [35,37]. The marital status of the participants was significantly associated with better physical health, perceived health, and overall health, which is consistent with previous studies indicating that married people enjoying better physical health [37,38].

Participants living in a nuclear family perceived better mental, social, and perceived health; however, they perceived less anxiety, depression, and anxiety-depression. The nuclear families try to problem-solve together and support each other and have more stable relationships. Families who had higher monthly income reported perceived better physical, mental, social, and perceived health, and self-esteem as well as they reported lower scores in disability, anxiety, depression, and anxiety-depression.

In addition, DMD/SMA groups reported higher scores in adaptability than the ADHD group and for 2007 DMD group [29] and Nan et al. [19] family residents in Hong Kong However, the ADHD group reported lower scores in partnership and overall family support than the DMD group, the TS/KS group, and Nan et al. [19] group. Correlation between family support and demographic variables were expressed male and higher monthly income families who had reported higher family support.

From hierarchical multiple regressions analysis, the large effect for social health then vulnerable status, marital status, and age as well entered in the final regression model showed that four predictors accounting for 35.3% of the variance in family support. The family role with satisfied marital status and age differences might make their health and support different. Vulnerable populations who are less likely to have a usual source of care if they are poorer or lack insurance or age increased [39]. Usual source of care provide for the vulnerable groups may promote their health care qualities and maintain their family support to facilitate their families health.

Limitations

The present study was still not representative of families of vulnerable children, as the sample used was not random. No data were recorded regarding the reason for non-participation, however, it was assumed that these people wanted to maintain their privacy and they were busy. Future research might employ composite scales to assess health, wellbeing, and family support measures and with larger samples using that integrate quantitative and qualitative methods toward development outcome based program research and incorporate practitioner perspective for evidence based practice.

Implications for policy and practice

The results suggest the efficacy to care for families of children regarding their physical health, mental health, self-esteem, and perceived health, and reducing anxiety, depression or anxiety-depression as shown in the DMD and SMA group, compared to the ADHD and the TS/KS families. It is critically important for health promotion strategies to provide the DMD/SMA and the ADHD families with comparatively more resources than the TS/KS families.

Social health was an important contributor to family support, which was highly positively correlated with overall health and subscales of positive health. Maintaining and increasing social and family support actions that were focused on as age increase, poor income, and activity severely limitation would be able to create a higher quality of life and resolve family health promotion problems to enable positive family function for the specify participants.

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**Contributions**

Study design: JYC, data collection and analysis: MCL, MCC, and manuscript preparation: JYC, HSC, MCC.

**Conflict of Interest**

The authors declare no competing interests.

**Ethical Approval**

Details of information brochure and informed consent were approved by KMUH IRB board (KMUH-IRB-2014058).

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