

Original article

Quality of life for primary caregivers of muscular dystrophy patients in South Korea

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Keywords: caregiver; quality of life; muscular dystrophy

Background Although some studies measured the burden of caregivers and the factors that influenced their feelings of burden, few studies have measured the quality of life (QOL) for primary caregivers of patients with muscular dystrophy (MD). We assessed the QOL for primary caregivers of patients with MD in South Korea and identified factors associated with caregivers' QOL.

Methods Ninety dyads of patients with MD and their primary caregivers were enrolled in this study. The QOL of caregivers of patients with MD was assessed subjectively using the World Health Organization Quality of Life Assessment, Life Brief Form. Caregivers' emotional status was assessed using the Beck Depression Inventory (BDI) and family function level was evaluated using the Family APGAR scale. Patients reported their emotional status using the BDI or the Children's Depression Inventory. The functional levels of patients were evaluated by the modified Barthel Index.

Results Caregivers' QOL was statistically associated with family income, family function, emotional status of patients, level of education, and emotional status of caregivers ($P < 0.05$). Caregivers who were employed had a significantly higher QOL than those who were not ($P < 0.05$). In multiple regression analyses, emotional and employment status of caregivers was strongly associated with caregivers' QOL.

Conclusion Rehabilitation teams should consider not only the physical factors of patients but also the psychological and demographic factors of primary caregivers of patients with MD.

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By the past several decades, pulmonary care had been remarkably improved resulting in increased longevity for patients with muscular dystrophy (MD). These improvements have also created a longer period of dependency of patients on caregivers. Despite longer periods of dependency, many people with MD in South Korea continue to live at home thanks to informal caregivers who are usually one or more of the patients' family members. Being cared for by family members can have positive effects on patients and caregivers, such as the strengthening of family ties. However, the deteriorated physical condition of patients can impose great physical and mental burdens on caregivers as patients' longevity and dependency increase. The subjective quality of life (QOL) of patients' primary caregivers may be affected by impaired physical and mental health.¹⁻⁴ Therefore, environmental or emotional interactions that are likely to improve the QOL of the dyads need to be explored to establish an overall care protocol as a complement to medical information and to facilitate the care of MD patients while at the same time avoiding caregiver burnout.

Few studies have attempted to measure the QOL of primary caregivers of MD patients but there have been a few studies that measured the burden of caregivers and the factors that influenced their feelings of burden.⁵ This study was designed to assess the QOL of primary caregivers of MD patients living with patients at home and to identify factors associated with their subjective

QOL. Assessment of QOL factors of caregivers may improve the mental health of caregivers and better assist them in the care of their patients.

METHODS

The study was a single centre, evaluation of family caregivers caring for patients with MD. All primary caregivers and their patient with MD who visited the outpatient clinic or were admitted to the Gangnam Severance Hospital in South Korea were enrolled in the study. All patients in the study were living at home with their families when they enrolled.

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After informed consents were obtained, self-administered questionnaires written in Korean, the primary language of the participants, were completed by the dyads. Patients who had difficulty filling out the questionnaires due to physical limitations were assisted by study social workers.

The variables of interest concerning primary caregivers of patients with MD are as follows: the type of MD of the patient confirmed by muscle biopsy or DNA analysis, the degree of dependency on personal care measured by the modified Barthel Index (MBI),⁶ the subjective QOL of caregivers measured by the Korean version of the World Health Organization Quality of Life Assessment, Life Brief Form (K WHOQOL BREF),⁷ the emotional status of caregivers measured by the Korean version of the Beck Depression Inventory (K BDI),^{8,9} and the level of family function measured by the Korean version of the family APGAR scale.¹⁰ Demographic data of caregivers were also collected. The emotional status of patients was evaluated by K BDI and the Korean version of the Children's Depression Inventory (K CDI)¹¹ evaluated the emotional status of patients under 18 years of age. The validities and the reliabilities of Korean version of above evaluation tools had been documented.^{7,11}

The WHOQOL assessment instrument^{12,13} is a self-reported, multidimensional measure that assesses not only an individual's physical health but also the psychological, social and spiritual elements of his or her life. While the WHOQOL allows a comprehensive assessment of QOL, sometimes in a practical sense, it is too cumbersome to be adequately implemented. To enable a brief but accurate assessment of QOL that was more convenient for use in large research studies or clinical trials, the WHOQOL BREF¹⁴ was developed. The WHOQOL BREF contains 26 items grouped into the five domains of overall QOL and general health, physical health, psychological health, social relationships, and environment. It is based on a Likert type scale of 1 to 5. The highest score is 130 and higher scores imply a higher QOL.

BDI¹⁵ is a 21-item scale that gathers information on different symptoms of depression. Each item on the scale is scored from 0 to 3. It provides information on both the presence and severity of depression. A score above 10 out of 63 indicates depression and higher scores imply the presence of more severe depression.

The family APGAR scale was introduced to assess adult satisfaction with social support received within a family.¹⁶ It draws its name from a 5-item measure of perceived family support in the domains of adaptation, partnership, growth, affection, and resolve. The statements focus on the emotional, communicative and social interactive relationships between the respondent and his or her family members. Each item on the scale is scored from 0 to 2 and higher scores imply improved family function. A total score from 0 to 3 implies severe dysfunction, while a

score from 4 to 6 indicates moderate family dysfunction and a score from 7 to 10 indicates optimal family function.

CDI^{17,18} is one of the most widely used depressive symptomatology, self rating scales for children. Consisting of 27 self reported items, CDI was modelled after BDI to assess affective, cognitive and behavioural symptoms of depression in youth. Each item on the scale is scored from 0 to 2, contributing to an overall CDI score that ranged from 0 to 54. A score higher than 13 implies depression, and higher scores imply the presence of more severe depression.¹⁷

Statistical analysis

We analyzed the data using the SPSS 13.0 (SPSS Inc., USA). Descriptive statistics, such as mean \pm standard deviation (SD), or ranges, on the collected data were calculated. We calculated Pearson correlation coefficients to examine the relation between independent and dependent variables. Statistical significance level was set at $P < 0.05$.

Caregivers were divided into two groups according to the characteristics of patients, such as Duchenne MD (DMD) vs. non-DMD and nondepressed patients vs. depressed patients. Caregivers were also grouped according to the characteristics of the caregiver, such as maternal vs. nonmaternal relationship with the patient, unemployed vs. employed status and with vs. without religious belief. An independent *t* test was used to measure the differences of QOL between each group.

We used linear regression with stepwise variable selection to identify factors associated with the QOL of primary caregivers. Family income, family Apgar score, presence of depression in patients (coded using dummy variables), level of education, BDI score and vocational status (coded using dummy variables) of caregivers were among the factors selected for possible inclusion in the regression model.

RESULTS

Subject description

A total of 90 MD patient/caregiver dyads were enrolled in the study. Table 1 details patients' characteristics. Table 2 presents the characteristics of the caregivers.

Dependent and independent variable relationships

We observed that QOL scores of caregivers were statistically associated with family income, family APGAR score, CDI scores of caring patients, level of educations and BDI scores of caregivers (Table 3). Higher family income, improved family function and higher levels of education were associated with a higher QOL of caregivers. Depression in caregivers and patients less than 18 years of age were associated with a lower QOL of caregivers. However, duration of care giving,

Table 1. Characteristics of patients with muscular dystrophy

Characteristics	Values
Gender (n (%))	
Male	86 (95.6)
Female	4 (4.4)
Age (years)	14.5±7.3 (8–42)
Functional level (MBI)	50.0±34.2 (0–100)
Affection (BDI or CDI) (n (%))	
Not depressed	35 (38.9)
Depressed	55 (61.1)
Type of muscular dystrophy (n (%))	
Duchenne	67 (74.4)
Becker	3 (3.3)
Myotonic	5 (5.6)
Limb girdle	4 (4.4)
Congenital	1 (1.1)
Undetermined	10 (11.1)

If not otherwise reported, values are mean ± SD and range. MBI: modified Barthel index. BDI: Beck depression inventory. CDI: children’s depression inventory.

Table 2. Characteristics of primary caregivers

Characteristics	Values
Age (years)	42.9±8.7 (18–71)
Relationship to patient (n (%))	
Mother	81 (90.0)
Father	4 (4.4)
Other	5 (5.6)
Duration of care giving (years)	7.5±4.5 (0.5–25)
Religion (n (%))	
Not applicable	17 (18.9)
Applicable	73 (81.1)
Education (years)	11.8±3.2 (3–18)
≤6 (n (%))	10 (11.1)
7–9 (n (%))	9 (10.0)
10–12 (n (%))	50 (55.5)
≥13 (n (%))	21 (23.3)
Employment (n (%))	
Unemployed	51 (56.7)
Employed	39 (43.3)
Monthly household income (US\$)	1921.1±1350.0 (300–6000)
<999 (n (%))	27 (30.0)
1000–1999 (n (%))	36 (40.0)
>2000 (n (%))	27 (30.0)
Affection (BDI)	16.2±15.6 (0–63)
Not depressed (n (%))	31 (34.4)
Depressed (n (%))	59 (65.6)
Family function (family APGAR)	5.9±2.0 (0–10)
Good (n (%))	43 (47.8)
Moderate dysfunction (n (%))	33 (36.7)
Severe dysfunction (n (%))	14 (15.6)
QOL score	76.2±20.5 (11–120)

If not otherwise reported, values are mean ± SD and range. US\$: US dollar. BDI: Beck depression inventory. QOL: quality of life.

Table 3. Correlation coefficients between QOL of caregivers with other variables

Variables	r values	P values
Duration of care giving	-0.180	0.089
MBI	0.123	0.247
Family income	0.320	0.002
Family APGAR	-0.276	0.008
BDI (Patient ≥18 years)	-0.188	0.245
CDI (Patient <18 years)	-0.403	0.004
Age (Caregiver)	-0.185	0.083
Education duration (Caregiver)	0.379	0.000
BDI (Caregiver)	-0.759	0.000

QOL: quality of life. MBI: modified Barthel index. BDI: Beck depression inventory. CDI: children’s depression inventory.

MBI scores of patients, BDI scores of patients, and caregiver age did not reveal significant correlations with QOL scores of caregivers.

Caregivers who were employed showed significantly higher levels of QOL than those who were not ($P=0.009$). However, caregivers’ QOL compared according to patients’ diagnoses, relationship to the patient, religious affiliation and the existence of patients’ depression did not reveal significant differences (Table 4).

Table 4. Comparison of QOL of caregivers according to characteristics of patients and caregivers

Variables	n	QOL	P values
Diagnosis			0.583
DMD	67	75.5±22.3	
Non DMD	23	78.2±14.1	
Relationship to patient			0.583
Mother	81	75.8±21.1	
Other	9	79.7±14.9	
Employment			0.009*
Unemployed	51	71.3±23.3	
Employed	39	82.6±14.0	
Religion			0.855
Not applicable	17	75.4±23.4	
Applicable	73	76.4±19.9	
Emotional status of patient			0.488
Not depressed	35	76.1±22.4	
Depressed	55	73.1±19.0	

Values are mean ± SD. *Comparisons with *t* tests significant at $P < 0.05$. QOL: quality of life. DMD: Duchenne muscular dystrophy.

Linear regression analyses

In linear regression analyses (Table 5), the emotional and employment status of caregivers accounted for 15.6% of caregivers’ QOL. BDI scores demonstrated a negative relationship with QOL scores. Higher BDI scores were associated with lower QOL scores, suggesting that severe depression was associated with lower QOL. Employment status was demonstrated by a positive relationship with QOL scores, indicating that employed caregivers had a higher QOL.

Table 5. Linear regression models using significance values and adjusted R^2 to predict QOL of caregivers

Predictors	Unstandardized β	SE	Standardized β	P values	Adjusted R^2 (SE)
BDI of caregivers	-0.57	0.18	-0.31	0.002	0.156
Employment	9.91	4.04	0.24	0.016	(18.76)

QOL: quality of life. BDI: Beck depression inventory.

DISCUSSION

The QOL of primary caregivers of MD patients has received minimal attention although the psychological and physical importance of this work has been recognized.¹⁹⁻²¹ Caregivers can play a major role in improving or aggravating patients’ QOL, which can affect the outcome or progress of patients’ treatment. Therefore, in caring for patients one should consider caregivers’ QOL for improving the QOL of both patients and caregivers.

In our literature search, few studies examining the QOL

of caregivers of MD patients were found. However, possible factors of caregivers' QOL include the characteristics of the caregiver (e.g., age, marital status, mental health, education),²²⁻²⁴ characteristics of the patient (e.g., the degree of disability, mental health),^{22,25} social factors,²² economic levels,^{22,26} and cultural context.²⁶ As we observed, caregivers' QOL was related to various factors including the characteristics of patients, such as emotion, as well as the characteristics of caregivers, such as emotion, level of education, social factor (employment status), economic level (family income), and family function. We need to understand not only the importance of each factor separately but also the relationships between the factors.

The QOL of caregivers showed no significant differences between the caregiver groups with regard to caring patients, DMD with rapider progression vs. non-DMD with slower progression. MBI scores of caring patients did not reveal significant correlations with QOL scores of caregivers. On the other hand, the emotional status of patients, particularly under 18 years of age, was related to caregivers' QOL. We were extremely interested in this result rather than MD patients' physical disabilities or progression rate of disease, emotional status of younger patients was related to caregivers' QOL. It can be assumed that patients under 18 years of age better express their emotions to their caregivers because they are underage and still supposed to belong to their parents or family. We may need to focus more of our attention on the psychology of younger patients with MD and their relationship with their parents.

Education levels and caregivers' QOL showed positive correlations. This makes sense as higher education levels can contribute to employment opportunities and higher family income. There were positive correlations between levels of education and family income. Employed caregivers had higher levels of education than unemployed caregivers did. In multiple regression analyses, the emotional and employment status of caregivers among various parameters were more accountable for their QOL. Therefore, we will focus on the factors related to the psychosocial status of caregivers.

As previously stated, social functions of caregivers can affect their subjective QOL¹ and poor social functioning is a risk of an increased perceived care burden.⁵ We estimate that more than 90% of Korean MD patients live at home and are cared for by one of their family members. In turn, almost all Korean MD patients can affect the social lives of their caregivers. Social isolation may bring not only psychological stress from being separated from the community but also financial stress regarding family income, as more than half of caregivers had financial problems because of caring for the patients. The root causes of social isolation are inadequate policies and insufficient facilities to accommodate patients with MD.

Therefore, improved integration of MD patients into society and recognition of them as individuals who should be cared by the community may help minimize the psychological impact and social isolation felt by caregivers.

Caregivers of patients with neuromuscular disease face challenges when dealing with the stress associated with the chronic disability of a family member and the prospect of a shortened lifespan with no hope of recovery; therefore, demonstrate signs of anxiety and depression.^{4,24} The present study found depression in two thirds of caregivers and 28.7% had moderate to severe depression. However, none of the caregivers with depression was receiving psychiatric treatment.

Traditions or cultural factors may negatively affect the caregivers' QOL. Koreans, although no accurate statistics exist, have a tendency to deny the existence of psychological problems and the belief that they need to be treated. Many caregivers answered that they regarded their depression as a natural result of circumstance and therefore incurable. This may indicate that there are many caregivers who live their lives with undetected or untreated depression.

Particular problems may arise due to the inherent nature of the child parent relationship. Many primary caregivers of the current study, especially mothers of patients who represented the majority of the caregivers, responded that they feel guilty about their children's condition because MD is a genetic disorder. This feeling of guilt may cause caregivers to feel more depressed and have a lower QOL. Perrin and colleagues²⁷ report that the burden of care may fall disproportionately on mothers who care for children with health problems. Furthermore, many Koreans incorrectly believe that almost all genetic disorders come from the mother's side, which may increase feelings of guilt for mothers, reproach between family members, and negatively affect family function. We need to further investigate whether this misconception is general or confined only to patriarchal societies and to determine how this affects caregivers' QOL.

A research has shown that family function played a central role in both the physical and the psychological health of caregivers.²⁸ Caregivers' QOL in our study had statistical correlations with family function. These findings suggest that the development of rehabilitation programs is necessary to support the well being of the families of MD patients. The rehabilitation team caring families of patients with long-term disabilities should develop interventions that nurture the family as a whole on the understanding cultural context.

For a practical example with the consideration of psychosocial condition of caregivers of MD patients and their family, as our centre does, each health care centre can hold regular gatherings for MD patients and their

caregivers. The main purpose of these meetings is to encourage social activity and the exchange of information on MD. We hope that these activities help patients and caregivers free themselves from social isolation and obtain new information about MD. It may also help to announce MD widely, which is not well known compared with other chronic diseases. Increased awareness of MD to the public may help the community regard MD patients as individuals who should be cared for instead of being treated as pariahs and it will minimize the negative psychological and social stress on caregivers.

The present study has several limitations. First, the cross sectional nature of the data makes it impossible to draw causal conclusions. Second, there is the possibility of a selection bias as our centre is located in the capital city and most of the patients in the study are residents of this or satellite cities. The main reasons of refusal to participate in this study were worries about time consumption and exposure of privacy, such as economical status and scholarship level. Therefore, the respondents who were recruited from the centre and agreed to participate in the study limit the potential generalization of the findings. Another limitation of the study was that we could not administer routine psychological evaluations to exclude patients with cognitive impairment. The cognitive function of MD patients may affect their BDI or CDI scores and caregivers' expectations or responsibilities on their patients.

Despite the study's limitations, it is a relatively early one focusing on the QOL of primary caregivers of patients with MD. Additional research on more MD patients and primary caregivers is necessary to determine the generalizations of the findings. Further researches will help to understand the QOL of both MD patients and caregivers and related factors, and find practical solutions to address the issues at hand.

Our results suggested that the emotional and vocational status of primary caregivers of MD patients were strongly associated with their QOL. Therefore, rehabilitation teams should address not only the physical aspects of patients with MD but also the psychological and demographic factors of primary caregivers.

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