Original Article

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Quality of Life and Its Associated Factors among Caregivers of Down Syndrome Children

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This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (http:// creativecommons.org/licenses/bync/4.0/) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited. Copyright© 2018 Mongolian National University of Medical Sciences **Objectives:** According to the definition by WHO, the quality of life (QoL) is determined by self-evaluation in the community depending on the people's goal, expectation and standards and the QoL is a result with positive and negative assessments to be measured by the individual aspects. QoL among caregivers of Down syndrome children is not well studied in many developing countries including Mongolia. The aim the study was to evaluate quality of life and its associated factors among caregivers of Down syndrome children. **Methods:** A community based, cross-sectional study was conducted among 70 caregivers of children with Down syndrome in Ulaanbaatar, Mongolia. Data on QoL was assessed by WHOQOL-BREF questionnaire. **Results:** About 40% of caregivers considered their QoL good and 54.3% of them considered their health as satisfactory. The mean value of four domains of QoL were slightly different but not statistically (p>0.05). **Conclusion:** Out of socio-economic indicators, caregivers' gender, educational level, family income, marital status, number of family members and chronic illnesses of parents and children's ages have a huge impact on QoL of caregivers. Additionally, environmental self-assessment was directly correlated with assessment of physical health, mental health, and social relation.

Keywords: Down Syndrome, Quality of Life, Caregivers

Introduction

Caregivers of a child with the diagnosis of developmental delay are known to deal with an ongoing, chronic situation in supporting their child's various needs throughout their life [1]. Having a baby with Down Syndrome (DS) diagnosis was reported just after birth as emotionally overwhelming and stressful for all families. People from different cultures have different health

beliefs, understandings and social expectations in terms of caring for the developmental delayed children [2]. An increase in the risk for stress, exhaustion and more negative effects and poor health as result of having a child with a disability was reported [5]. The mothers of children with DS had significantly lower, less favorable scores than the fathers of children in DS vitality domain (p<0.0005) to determine self-perceived health among caregivers. The mothers also spent much more time with

DS children than anyone in the family, showing significant health worsening than their spouses and the control mothers [2, 4].

The World Health Organization (WHO) defines the quality of life (QoL) as the individual's perception of his/her position in life in the context of the culture and value system in which he/ she lives and in relation to his/her goals, expectations, standards and concerns. This definition reflects the view that QoL refers to a subjective evaluation which is embedded in a cultural, social and environmental context. Because this definition of QoL focuses upon respondent's "perceived" QoL, it is not expected to provide a means of measuring in any detailed fashion symptoms, diseases or conditions, but rather the effects of disease and health interventions on guality of life. As such, QoL cannot be equated simply with the terms "health status", "lifestyle", "life satisfaction", "mental state" or "wellbeing" [6]. Previous studies have highlighted the need to examine the multidimensional, holistic concept of QoL to determine the mental and physical health of caregivers of a child with mental disability [7, 8]. The field of intellectual disability is strongly influenced by the QoL paradigm, from a research, a practice-based, and a policyoriented perspective.

From several studies across different sociocultural contexts parents, especially mothers, having a child with disabilities were reported to perceive lower QoL in relation to their psychological wellbeing and physical health, as compared with mothers who had children who were not disabled or developing 'typically', due to increased care demands [9, 10]. The lack of family economic or material resources and its strong association with dissatisfaction with life, higher levels of psychological stress, and decreased the level of wellbeing among mothers with a child with disabilities has been cited [11]. Mothers of children with cerebral palsy demonstrated that the impact of increased caregiving demands, low maternal education and ethnic background led to higher levels of stress [12]. Significant association of caregivers employment, education level and ethnicity, stress index has also been reported [12, 13]. Many of the studies related to parents' or mothers' experiences and perceived QoL were conducted in Western developed countries. Although this does not negate the value of the findings, there are fundamental differences between these countries and Mongolia in terms of the cultures and health care systems that have an impact on parent's experiences of care [14]. The effects of having a child with DS on the QoL of Mongolian caregivers are not known. Insights into caregivers perceived QoL in relation to different life domains could serve to influence policy-makers in developing care priorities and strategies to be put in place. The findings could also add on to the knowledge base and insights in relation to parenting a child with DS in a socioeconomically and culturally diverse setting. So in this study, we aimed to examine the perceived QoL among caregivers with a child with DS, and also the relationship between selected background variables (i.e. education, income, maternal age, marital status, employment, the gender of caregivers) and their QoL.

Materials and Methods

Procedure and participants

This research study was done from 2013 to 2016 and was funded by Mongolian-Taiwan grant. Seventy participants including 64 mothers and 6 fathers who were the biological parents of DS child (aged 18 years and younger) were enrolled in the study.

The ethics approval was obtained from the Ministry of Health, Mongolia. Informed consent was obtained from the caregivers before the data collection. WHOQOL-BREF 26 questionnaire was used to assess the QoL among caregivers. The WHOQOL-BREF questionnaire has 2 sections with 26 questions. There are two questions in main part, and an additional 24 questions in next section. The additional questionnaire has been divided into 4 domains: physical health, mental health, social interaction and environmental support.

Assessment of quality of life

A cross-sectional approach using the 26 item The World Health Organization Quality of Life scale (WHOQOL-BREF) instrument to assess the four life domains of caregivers, namely their physical health, psychological well-being, social relationship with others and environmental support domains, was adopted in this study [6]. The QoL instrument uses the 5-point Likert-type scale to elicit participant's responses in relation to their four main life domains. These are the physical health with 7 items domains (DOM1), psychological wellbeing with 6 item (DOM2), the social relationship with 3 item (DOM3), and the environmental support with 8 item (DOM4). Also included are two single-item questions related to the rating of QoL (Q1) and satisfaction with own health (Q2). It has an acceptable internal consistency reliability of Cronbach's alpha coefficient of 0.7–0.9.

Statistical analysis

The mean of all the 2 items were calculated to determine the overall QoL and the four domain-specific QoL scores were analyzed separately. Spearman's rank-order correlations were used to assess the correlation between the selected demographic variables and the overall and domain-specific QoL scores; Chi-square test was applied to analyze categorical variables and t-test for continuous variables. ANOVA used to compare the means of more than two groups. P<0.05 was regarded as a statistical significance in all analyses. These analyses were done using STATA data analysis and statistical software (College Station, Texas, USA).

Results

A total of 64 (91.4%) mothers and 6 (8.6%) fathers were recruited for our study and their mean age was 40.6 ± 5.7 . When categorized by age, parents who were 40-44 years old formed the largest group (n=16, 22.9%), followed by those aged 35-39 (n=15, 21.4%) (Figure 1).





In terms of education, we found that over two-thirds of the parents in our study were college graduates (n=48, 68.6%), while about one-forth were high school graduates (n=18, 25.7%). As reported in 2013, Mongolians with a college education counted for 16.7% of the population, with 25.5% having a high school diploma, while in capital city of Ulaanbaatar 25.7% of people have a college education and 29.6% are high school graduates [15]. By marital status, 55 (78.6%) of the parents in our study were married, whereas 3 (4.3%) were single mothers. According national survey done in 2013, 62% of all households were married and 11% of all were families with single parents [16].

Families with five or more members were the most common type in our study (n=30, 42.9%), whereas smallest group was families with three people (n=13, 18.6%). The National survey done in 2010, indicated that most common family size in Mongolia is three to four people accounting for 47.1% of the population, which in contrast to larger family size identified in our study [16]

Out of the parents in our study, 6 (8.6%) reported some chronic diseases, while 64 (91.4%) were indicated their health status as healthy (Table 1). We evaluated QoL of caregivers using the 26 questions in WHOQOL-BREF which included 2 main and 24 additional questions.

Our participants evaluated their total QoL as "Good", scoring 3.28 ± 0.906 (mean \pm standard deviation). Their health status was assessed as mainly "Satisfied", scoring 3.44 ± 0.819 .

Remaining 24 questions of WHOQOL-BREF were classified into four different domains and mean values are shown in Table 2. We found that, the highest values were in the domain of social interaction including personal interaction with others, society support and intercourse, while the lowest scores were in domain personal health status, diseases, life energy, work capability had of health status (64.1 ± 15.73 vs. 50.7 ± 11.2). We did not observe any statistical differences between four groups, even though the raw data showed slight differences in numbers (p>0.05).

Caregivers rated their "psychological status" by selfesteem, positive and negative thoughts, thinking, memory and attentions with higher scores, whereas they rated their economic status, family relations and environment hazardous with lowest scores in "environmental domain" (63.2 ± 14.5 vs. 51.7 ± 16.74). There was no statistical difference between two domains of "physical health" and "social interaction" (p>0.05). In other words, caregivers with DS children were within the normal range (Table 2).

Values for the psychological status, environmental, physical health and social interaction domains were analyzed correlating the age of the children they cared for and we observed slight tendency of decreasing scores with increasing age, but it was not statistically different (p>0.05). However, there was a medium strength correlation between these four domains (r=0.371, r=0.603, p<0.001, Table 3).

We analyzed whether there are factors influencing QoL such as caregivers age, gender, education level, marital status, maternal age during pregnancy and chronic diseases of caregivers' and did not observe any differences.

| Table 1. Soc | io-Economic status | of caregivers | with Down | Syndrome children |
|--------------|--------------------|---------------|-----------|-------------------|
|--------------|--------------------|---------------|-----------|-------------------|

| Indications | Group | n | % |
|----------------------------------|------------------|----|------|
| | Secondary school | 4 | 5.7 |
| Education | High school | 18 | 25.7 |
| | College | 48 | 68.6 |
| | 20-24 | 7 | 10.0 |
| | 25-29 | 11 | 15.7 |
| Age at pregnancy with a DS fetus | 30-34 | 16 | 22.9 |
| | 35-39 | 24 | 34.3 |
| | 40-44 | 12 | 17.1 |
| | <3 | 13 | 18.6 |
| Number of family members | 4 | 27 | 38.6 |
| | ≥5 | 30 | 42.9 |
| | Married | 55 | 78.6 |
| | Living together | 4 | 5.7 |
| Marital status | Separated | 4 | 5.7 |
| | Widow | 4 | 5.7 |
| | Single parent | 3 | 4.3 |
| Chronic disorders | Yes | 6 | 8.6 |
| | No | 64 | 91.4 |

Table 2. A comparison between domains of WHOQOL-BREF

| Oal domains | Maan (CD | 95 | n value | |
|-----------------------|------------|------|---------|---------|
| QOL domains | Mean ±5D – | Low | High | p-value |
| Physical health | 50.7±11.2 | 48.0 | 53.4 | |
| Mental health | 63.2±14.5 | 59.7 | 66.7 | |
| Social interaction | 64.1±16.3 | 60.1 | 68.0 | 0.36* |
| Environmental support | 51.7±16.74 | 47.7 | 57.7 | |

*No p-value was significant at the 0.05 or higher level using Anova test.

Table 3. Domains of QoL and its correlation to DS children age

| QoL domains | Children age | Physical health | Mental health | Social interaction | Environmental support |
|-----------------------|--------------|-----------------|---------------|-----------------------|-----------------------|
| Children age | 1 | | | | |
| Physical health | -0.10 | 1 | | | |
| Mental health | -0.06 | 0.37ª | 1 | | |
| Social interaction | -0.14 | 0.45ª | 0.53 | ^{ia} 1 | |
| Environmental support | -0.16 | 0.63ª | 0.55 | a 0.53ª | 1 |

^a- Correlation significant at the 0.01 level (2-tailed).

We also correlated gender as a factor with QoL. Paternal self-assessment among domains of physical and psychological domains was slightly higher than maternal self-assessment, meanwhile maternal self-assessment of environmental domain was higher than paternal assessment, but were not statistically significant (p>0.05). We believe that these result may be caused by the small number of fathers recruited in our study.

There was a tendency to have lower assessment of the

| Out damains | | Mean ±SD | 95 | % CI | |
|-----------------------|----|-----------|------|------|---------|
| QOL domains | n | Low | High | | p-value |
| Physical health | | | | | 0.427 |
| 3 | 13 | 52.6±8.1 | 47.5 | 57.7 | |
| 4 | 27 | 48.5±10.4 | 44.3 | 52.7 | |
| > 5 | 30 | 51.9±12.7 | 47.1 | 56.7 | |
| Total | 70 | 50.7±11.2 | 48.0 | 53.4 | |
| Mental health | | | | | 0.073 |
| 3 | 13 | 63.8±8.9 | 58.1 | 69.4 | |
| 4 | 27 | 58.4±15.8 | 52.0 | 64.8 | |
| >5 | 30 | 67.2±14.1 | 61.9 | 72.5 | |
| Total | 70 | 63.2±14.5 | 59.7 | 66.7 | |
| Social interaction | | | | | 0.033* |
| 3 | 13 | 53.8±15.4 | 44.5 | 63.2 | |
| 4 | 27 | 65.0±14.6 | 59.0 | 71.0 | |
| >5 | 30 | 67.8±16.7 | 61.4 | 74.2 | |
| Total | 70 | 64.1±16.3 | 60.1 | 68.0 | |
| Environmental support | | | | | 0.261 |
| 3 | 13 | 51.0±15.4 | 41.7 | 60.4 | |
| 4 | 27 | 48.0±16.0 | 41.5 | 54.4 | |
| >5 | 30 | 55.3±17.3 | 48.7 | 61.8 | |
| Total | 70 | 51.7±16.5 | 47.7 | 55.7 | |

| Table 4. QoL is related with | number of family members |
|------------------------------|--------------------------|
|------------------------------|--------------------------|

*No p-value was significant at the 0.05 or higher level using trend test.

caregiver's physical health with higher education, and higher evaluation of the other three other domains, but this too was not statistically different (p>0.05).

QoL was statistically significantly correlated with the number of family members, especially QoL was higher in families with five or more members (p>0.05) as well as scores in the environmental domain (p<0.05, Table 4). It could be that larger number of family members increases the number of people to take of DS children or because of better social welfare supports for families with many children.

The QoL of caregivers was statistically different between groups according to marital status. Married people had higher QoL than single parents, especially in domains of psychological health and environment (p<0.05, Table 5). The chronic disease status of caregivers was not correlated with their total QOL (p>0.05), however their psychological and physical health domain assessments were lower (p<0.05).

QoL of caregivers were studied correlating to DS child's age

and their congenital birth defects. We observed that there is a tendency of QoL reducing over the years, but not statistically significantly (p>0.05). Also, congenital birth defects of DS children tended to cause a slight lowering of QoL of their caregivers, but this was not confirmed statistically (p<0.05, Figure 2).

We observed in our study that percentage of parents who rated their QoL as "Satisfied" was higher in parents of children with congenital birth defects than in parents of children without defects (57.4% vs 47.8%), but "well-satisfied" answers were lower in parents of children with congenital birth defects. Also there none of the parents of children without congenital birth defects rated their QoL as "Totally unsatisfied" in (p<0.05, Figure 3).

Congenital birth defects of DS children tend to adversely affect all domains of QoL of their caregivers but not statistically significantly (p>0.05). Congenital birth defects are not correlated with lower scores in all domains, neither are the education level of parents and caregivers' age.

Table 5. QoL and marital status among participants

| Oct demoine | n Moon (SD | | 95% CI | | |
|-----------------------|------------|-----------|--------|-------|---------|
| QOL domains | n | Mean ±SD | Low | High | p-value |
| Physical health | | | | | 0.467 |
| Married | 55 | 53±51.1 | 1.4 | 48.2 | |
| Living together | 4 | 49.1±10.3 | 32.8 | 65.4 | |
| Separately lived | 4 | 57.1±10.5 | 40.4 | 73.9 | |
| Widow | 4 | 42.6±22.0 | 7.5 | 77.6 | |
| Single | 3 | 48.8±10.9 | 21.7 | 75.9 | |
| Total | 70 | 50.7±11.2 | 48.0 | 53.4 | |
| Mental health | | | | | 0.050 |
| Married | 55 | 64.9±13.8 | 61.1 | 68.7 | |
| Living together | 4 | 61.5±4.0 | 55.1 | 67.8 | |
| Separately lived | 4 | 62.5±3.4 | 57.1 | 67.9 | |
| Widow | 4 | 46.0±23.4 | 8.8 | 83.2 | |
| Single | 3 | 59.7±22.9 | 2.7 | 116.7 | |
| Total | 70 | 63.2±14.5 | 59.7 | 66.7 | |
| Social interaction | | | | | 0.081 |
| Married | 55 | 66.0±16.7 | 61.4 | 70.6 | |
| Living together | 4 | 60.4±8.0 | 47.7 | 73.1 | |
| Separately lived | 4 | 57.3±8.6 | 43.6 | 71.0 | |
| Widow | 4 | 47.2±24.1 | -12.5 | 107.0 | |
| Single | 3 | 61.1±12.7 | 29.5 | 92.7 | |
| Total | 70 | 64.1±16.3 | 60.1 | 68.0 | |
| Environmental support | | | | | 0.012* |
| Married | 55 | 53.3±15.7 | 49.0 | 57.5 | |
| Living together | 4 | 59.4±10.8 | 42.1 | 76.6 | |
| Separately lived | 4 | 51.6±16.2 | 25.7 | 77.4 | |
| Widow | 4 | 27.1±26.0 | -37.6 | 91.7 | |
| Single | 3 | 37.5±0.0 | 37.5 | 37.5 | |
| Total | 70 | 51.7±16.5 | 47.7 | 55.7 | |

*No p-value was significant at the 0.05 or higher level using trend test.

Discussion

In our study, we found that our participants had much higher education versus national levels, as the proportion of college graduates were as 68.6% and 16.7%, respectively. Furthermore, as this research work was done in capital city, Ulaanbaatar, we compared it with its citizens and found the same tendency with 25.7% being college graduates [15]. This pattern also observed in a research done in Brazil among caregivers of DS children, as reported by 22% were college graduates versus 15% at the national level [17]. We believe that college-educated men and women married at older ages compared with their counterparts who had fewer years of schooling, therefore they had children at older age, with its known increased risk for having DS children. College graduates and those with less education married at approximately the same rates, but college graduates married later (at age 24.9 vs. 22.8) [18].

Regarding the two general questions about QoL, our participants evaluated their total QoL as "Good" 50% of the



Figure 2. Percentage of QoL and congenital birth defects among DS children



Figure 3. QoL and its percentage congenital birth defects.

time while 33% rated their QoL as "neither poor nor good", similar results with the study done in Brazil [17]. Concerning the question "How satisfied are you with your health?", 58.5% of the parents/caregivers stated they were "satisfied" and 1.5% stated they were "very satisfied", while 30% "neither satisfied nor dissatisfied" and 1.5% felt themselves "dissatisfied". These results were in contrast with the previous study [17].

Our results parallel other research with social domains scores

much higher than environmental domain scores (63.2 ± 14.5 vs. 51.7 ± 16.74), indicating that the financial resources and leisure activities are greatly affected in such families [19]. The mothers with DS children who had their own home reported much higher QoL in their physical and environmental health assessment rather compared to families living in rental houses [20]. These results are in line with other research and emphasize the importance of family support services from the public sector in Mongolia, which

must be driven as a national policy.

Other researchers have found that parents have lower QoL if their children have difficulties with physical activity rather than mental developmental delay, but this was not observed in our study [19]. In contrast, behavioral and developmental disability were associated with higher parenting stress than medical disability [21].

Even though we did not observe any statistical differences while analyzing a correlation of DS children age and QoL, there is other research by Eisenhower, Baker and Blacher identified an increase in caregiver stress as the child with Down syndrome [22]. The longitudinal studies indicate that stress levels of parents of children with Down syndrome increase over the early to middle childhood period, suggesting that more research should be directed at delineating moderators of stress beyond the infant and toddler years [23].

The importance of family relationships to the wellbeing of all family members has been highlighted by the review of scientific evidence of early childhood by Shonkoff and Phillips [24]. The way in which the family functions may serve as a buffer or promoter of parenting stress. For example, in our study we observed that families with many members have lower stress and higher QoL of parents. Out of many research studies done to assess the QOL of caregivers, the main implication is there are significant differences in the QOL of parents having a child with a disability based on the type of disability the child had [21, 25-28].

The main limitation of this study was recruitment of study subjects were only from capital city of Mongolia. Therefore, educational level of participants was higher than average educational level of nation. Further comparison studies among broader and more general population groups are needed to affirm current findings.

In conclusion, we identified that out of socio-economic indicators, caregivers' gender, educational level, family income, marital status, number of family members and chronic illnesses of parents and children's ages influence fact the QoL of caregivers with DS children.

Conflict of Interest

The authors have no conflict of interests.

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