

BRIEF RESEARCH COMMUNICATION

A pilot study of mental health and quality-of-life of caregivers of children with cleft lip/palate in India

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ABSTRACT

Background: There has been insufficient and contradictory research to date on the impacts of caring for a child with cleft lip/palate. Therefore this pilot study sought to investigate the mental health and quality of life of primary caregivers of children with cleft lip/palate.

Materials and Methods: Seventy-nine primary caregivers of children with cleft lip/palate awaiting a surgical procedure in India completed questionnaires to measure their mental health, quality of life, and demographic variables.

Results: The results indicated that half of the sample suffered from poor mental health and a reduced quality of life. Overall perceptions of quality of life were significantly associated with the age of the child requiring care and the contact hours per day spent with the child.

Conclusion: It is apparent that caregivers for this population do suffer from a reduced quality of life and poorer mental health. This is especially relevant for older caregivers and those with greater caring responsibilities.

Key words: Caregiver, cleft lip/palate, mental health, quality-of-life

INTRODUCTION

In recent times there has been a surge in research assessing the Quality-of-Life (QOL) of individuals suffering from different anomalies' and illnesses. Conversely there has been little research assessing the QOL of caregivers, especially the QOL of caregivers of children with craniofacial abnormalities. Specifically, Yazdy *et al.*^[1] highlighted the need for QOL to be assessed in caregivers of children who have cleft lip/palate (CL/P). Although several studies have been conducted assessing Mental Health (MH) and QOL in caregivers of children with CL/P,^[2-4] the field still lacks a clear understanding of the specific aspects of caregiving in the context of CL/P that impact upon the QOL.

CL/P is a craniofacial abnormality that affects approximately

1 in 700 live births occurring more frequently in Indian and oriental populations.^[2] Having an infant or child with CL/P presents distinct challenges to the caregiver. As children can experience multiple difficulties from birth, such as difficulties related to feeding, hearing, speaking along with having to undergo in some instances multiple surgeries.

The little research that has been conducted thus far has found conflicting results. Speltz *et al.*^[5] found that mothers of children with craniofacial abnormalities experience more stress and marital conflict than their peers. Whereas Kramer and colleagues^[6] found that CL/P had little impact upon parents QOL. Therefore this pilot study investigates the MH and QOL of caregivers of children with CL/P in order to delineate specific variables that significantly impact upon the MH and QOL of carers.

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MATERIALS AND METHODS

Participants

Seventy-nine primary caregivers of children with CL/P (<12 years) participated; 81% were mothers with a median age between 20 and 30 years.

Methods

The General Health Questionnaire – 12 (GHQ; 7) was utilized to assess MH. The WHOQOL-BREF^[7] was utilized to measure QOL. A demographics questionnaire measuring child, parent and care variables was also utilized.

Procedure

Caregivers of children with CL/P (<12 years) who were about to undergo a corrective surgical procedure in a charitable hospital in India were requested to participate. All participants provided informed consent. Participants who could not read English or Kannada were excluded from this pilot study. All participants completed the GHQ-12,^[8] the WHOQOL-BREF^[7] along with the demographic questionnaire.

Data analysis

The participants were divided into two groups based upon their scores on the GHQ.^[8] Participants who had a score ≥ 4 formed the caseness group and participants with a score < 4 formed the noncaseness group. Caseness was defined as probable psychiatric morbidity. The GHQ^[8] cut-off was taken as 4 in order to balance out the effect of stress and discomfort caused by the pending surgical procedures.

Descriptive statistics summarize the child and caregiver variables. Pearson correlations were conducted to ascertain the association between the measures and child and caregiver variables. Further *t*-tests were performed to test for a difference between the caseness and noncaseness groups.

RESULTS

Demographics of the sample

Seventy-nine primary caregivers of children with CL/P participated; 81% were mothers in the age range of 20-30 years (62%) with two children less than 12 years of age (39.2%). More than half the sample spent 12 hours or more with the child they cared for a day (55.7%). The vast majority of caregivers had access to other caregivers (97.5%) and no other disabled children in their care (97.5%).

The sex of the children with CL/P was relatively equally distributed with 45.6% being male and 54.4% being female. The majority of the children were ≤ 12 months of age (38%) and were an only child (34.2%).

QOL of the sample

Table 1 below displays the means and standard deviations of the participants scores on each of the domains of QOL, QOL

Table 1: Descriptive statistics of the QOL facet scores

	Mean	Standard deviation
Physical domain	24.8	4.6
Psychological domain	18.7	3.9
Social relationship domain	10.5	2.3
Environmental domain	24.0	5.5
QOL item 1 (overall QOL)	3.0	0.9
QOL item 2 (health satisfaction)	3.4	0.9
QOL total	84.6	15.6

QOL – Quality-of-life

total, and the two WHOQOL-BREF items that are analyzed independently, namely perception of overall QOL (item 1) and overall health satisfaction (item 2).

Pearson correlation coefficients were computed to analyze the association between the QOL facet scores and the age of the child as well as contact hours per day. The results of the analysis indicated a significant association between item 1, overall perception of QOL, and age of the child ($r = -0.26$, $P < 0.05$) as well as contact hours per day ($r = 0.28$, $P < 0.05$). No other correlations attained statistical significance.

Comparison of the caseness and noncaseness groups

The distribution of the caregiver's scores on the GHQ was almost equivalent across the sample, with 42 participants scoring < 4 (53.2%) and comprising the noncaseness group and 37 scoring ≥ 4 (46.8%) and forming the caseness group. Caseness was defined as probable psychiatric morbidity.

Independent sample *t*-tests were conducted to compare the caseness and noncaseness groups across the caregiver and child demographic variables. A significant difference was found between the ages of the caregivers in the caseness and noncaseness $t(77) = 2.7$, $P < 0.01$. No significant difference was found between the caseness and noncaseness groups for the other caregiver demographic variables. For the child demographic variables only birth order was found to be significantly different between the caseness and noncaseness groups; $t(77) = 2.5$, $P < 0.05$.

The caseness and noncaseness groups were also compared for differences on items 1 and 2 of the WHOQOL-BREF. A significant difference was found between the groups on both overall QOL ($t(77) = 2.54$, $P < 0.01$) and health satisfaction ($t(77) = 4.47$, $P < 0.001$). A significant difference was also evident between the groups on their QOL total scores ($t(77) = 4.48$, $P < 0.001$).

DISCUSSION

The results of the current study indicate that almost half of the caregivers suffered from poor MH displaying probable psychiatric morbidity (caseness). There was a significant difference in caregiver age, birth order of the child as well as QOL scores between the two groups, with older

caregivers whose child with CL/P was not the first born suffering poorer MH and QOL.

These findings regarding the poor MH of almost half the caregivers in this study are in contrast to a study conducted by Weigel and colleagues.^[2] Their study found that mothers of children with CL/P did not significantly differ from controls on clinical levels of depression and anxiety.

Previous research assessing the QOL of caregivers of children with CL/P has also reported contradictory results. Weigel *et al.*^[2] found that the QOL of mothers of children with CL/P is comparable to that of controls. In contrast Kramer and colleagues^[6] found parents QOL to be dependent on the severity of the craniofacial abnormality of the child; with parents of children who are more severely affected reporting poorer QOL.

In the current study it was evident that overall perception of QOL (QOL item 1) was significantly inversely related to the age of the child and positively associated to the contact hours with the child per day. Demonstrating that caregivers of younger children perceived their QOL as lower, this could possibly be explained by the demands of caring for the infant. In accordance with this finding Baker and colleagues^[3] found that parent's with younger children with CL/P were less adjusted and more distressed than their peers with older children with CL/P.

The results also indicated that the more time the caregiver spent with the child the better they perceived their overall QOL to be. Previous literature has reported the positive benefits of caregiving; Eiserman^[9] conducted a small case study of parents of children with CL/P and found that caring for a child with CL/P had several positive outcomes.

Although this pilot study contributes to the current understanding of the impact of caring for a child with CL/P on caregivers MH and QOL; the study also has several limitations. Namely the study was cross-sectional in nature and did not employ a control group for comparison of MH and QOL scores. Future research should employ a longitudinal research design with the addition a control group for comparison.

Furthermore the sample size was only moderate and all participants' were recruited from the same institution therefore limiting the generalizability of the results. Additionally the majority of the participants were mothers who may display differential adjustment in comparison to other caregivers. Therefore future research should seek to investigate the MH and QOL of other caregivers of children with CL/P.

In conclusion it is apparent that caring for a child with CL/P can lead to poorer MH and a diminished QOL. In the current sample this was especially relevant for older caregivers and the birth order of the child with CL/P. Additionally caregivers of younger infants also reported lower QOL scores. This highlights the need for clinicians to be aware of the detrimental effects of caregiver age, age of the child and other caregiving responsibilities upon the caregivers MH and QOL. Measures need to be taken not only to increase awareness of CL/P but also to help the caregivers adapt to the associated stressors and thus improve their QOL and MH. By improving the MH and QOL of the caregiver the treatment outcomes of the child with CL/P can also be improved.

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