

EMOTIONAL DISTRESS AND WELLBEING IN CAREGIVERS OF CHILDREN WITH CLEFT LIP AND CLEFT PALATE: MEDIATING ROLE OF SOCIAL ISOLATION

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ABSTRACT

The objectives of the research are 1) To assess the relationship in emotional distress, social isolation and psychological well-being among care givers of children with cleft lip and cleft palate. 2) To confirm mediating role of social isolation between emotional distress and wellbeing. This cross-sectional correlational research was conducted in Department of Psychology, University of Gujrat after approval from ASRB and data was collected between January to April, 2021. A sample of 200 caregivers visiting cleft hospital in Gujrat with their children who have cleft lip and cleft palate was purposively selected. There were 96 males and 104 females between age range 20 to 75 years old (M=34.71, SD=10.80). Majority was educated, residing in rural areas of Gujrat in joint family system. Urdu versions of three standardized scales were used for data collection, Caregiver Social Isolation Scale (CSIS, Shafiq & Amwar-ul-Mustafa, 2022), Psychological Wellbeing Scale (PWS, Boztepe, Çınar, & Özgür, 2020) and Depression, Anxiety, Stress Scale (DASS-21, Lovibond, & Lovibond, 1995) to measure emotional distress. Permissions were taken before using the scales from the test developers and translators. The results showed that there is a significant relationship between emotional distress (Depression, Anxiety and Stress), social isolation and psychological well-being among caregivers of children with cleft lip and cleft palate. Social Isolation has positive significant positive relationship with depression, Anxiety, stress and negative significant relationship with psychological well-being and has mediated either partially or fully among them. Depression has partially strengthened social isolation to mediate with wellbeing of caregivers. However, anxiety and stress has completely enhanced this withdrawal to weaken their sense of wellness. Implications are discussed in the light of the findings.

Keywords: Caregivers, Child, Hospitalized, Cleft Lip, Cleft Palate, Congenital Abnormalities, Social Isolation.

INTRODUCTION

All over the world, the child birth brings the wave of happiness and joy especially among the caregivers of child but sometimes this happiness changed in disparity, anxiety and worry when the child is born with any physical / mental disability or deformity. There are many types of deformities and disabilities (i.e. club feet, spina bifida, scoliosis, kyphosis, hyper-lordosis etc). Cleft lip and palate (CLP) is one forms of deformity. It is the most frequent congenital craniofacial malformation in humans and may has worse effects among care givers as far as their mental emotions & social status is concerned (Martelli, Coletta, Oliveira, Swerts, Rodrigues, Oliveira, & Martelli, 2015). The parents feel hesitation to meet people in their social circle and might be uneasy to fulfil their own social demands. Children and their families might be stigmatized due to cleft's effects on appearance and/or function (Goffman, 2009). Parents may experience in managing others' reactions to their child's cleft (i.e. their heightened sensitivity to the reactions of friends and family) the verbal and non-verbal expressions of distaste encountered in public and attempts to conceal their baby or shun social circumstances to avoid feeling different (Johansson, & Ringsberg, 2004).

In Pakistan, highest prevalence of children with cleft lip and cleft palate is in Punjab (67.4%), followed by Khyber Pakhtunkhwa (23%), Sindh (5%) and Azad Jammu and Kashmir (4.2%) (Sharif,

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Mahmood, Azhar, Asif, Zahid, Muhammad, Rehman, & Neil, 2019). So, the present study is focused on determining emotional distress (depression, anxiety, and stress), social isolation and psychological-wellbeing among the care givers of cleft lip and palate children. Emotional distress can also be defined as a combination of miserable psychological and biological symptoms. It is a condition that is characterized by the symptoms of depression (sadness, loss of interest, loneliness and hopelessness) anxiety (i.e. fear, agitation and feelings of tense) and stress (e.g. increased heart rate, sweating etc.). Excessive distress might increase a person's psychological burden. This may cause problem in thinking process, suicidal thoughts etc. So, it is very necessary to deal effectively with the situation or with the stressor for the good mental health (Razera, Trettene, Tabaquim, & Niquerito, 2017). The emotional state and social experiences of parents who have children with cleft lip and cleft palate deformity showed that 36% of participants were found fearful, and 19% reported sadness (Mirowsky, & Ross, 2002).

Social isolation is a multi-faceted construct that is defined as the insufficient quantity and/or quality of interactions with other persons, including those interactions that take place at the individual, group, and/or community level (Carvalho, Matos, Belchior, Araújo, Rocha, Neves, 2021; Zavaleta, Samuel, & Mills, 2017). It is a condition in which a person completely separates himself from the society and does not interact with others due to the feelings of shame or depression. He may spend more of his time alone. Likewise, care givers of cleft palate and lip sometimes become socially isolated because they might develop the feelings of sadness, hopelessness and embarrassment due to their cleft palate and lip children. Well-being is a complex concept but has been defined as an individual's sense of autonomy, personal growth, environmental mastery along with self-acceptance and positive association with other people, and a serene sense of aimful life (Ryff, 1995). The psychological health of the care givers having children with cleft lip and cleft palate on waiting list for palatoplasty posited that 43% mothers had moderate severe level of burden, effecting their wellbeing badly (Razera, Trettene, Tabaquim, Niquerito, 2017).

The research is aimed to explore the level of emotional distress, social isolation and well-being among the care givers of children with cleft palate and cleft lip. Generally all over the world and especially in Pakistan, where the parents or the caregivers of children with cleft palate and lip have to face the painful condition because their children are not like others, they have the problems in eating, feeding and speaking etc. In this situation most of the caregivers fall a prey to many psychological symptoms like depressive symptoms, anxiety symptoms and stress. Care givers isolate themselves from the society because they feel humiliation; they feel that people behaviour will not be appropriate with them. Social isolation is itself miserable condition for the parents or caregivers of cleft palate and lip children. Care givers often do not feel good and their overall psychological well-being is destroyed. The present study would help to understand emotional distress, social isolation and psychological well-being among care givers of children with cleft palate and lip. It is significant because if the care givers suffer from these conditions, so they might be in need of psychotherapy, counselling and guidance because their children problem is treatable and manageable. The hypotheses are 1) Higher the level of emotional distress, higher will be social isolation among caregivers of children with cleft lip and cleft palate. 2) Higher the level of emotional distress, lower will be the psychological well-being among caregivers of children with cleft lip and cleft palate. 3) Higher the level of social isolation, lower will be the psychological well-being among caregivers of children with cleft lip and cleft palate. 4) Caregiver social isolation would mediate between their emotional distress and wellbeing.

MATERIAL/SUBJECTS/PATIENTS AND METHODS

This cross-sectional correlational research design was conducted between January to April, 2021. Sample of two hundred individuals (96 males, 104 females) between age range 20 to 75 years old ($M=34.71$, $SD=10.80$) were taken from the care givers of children with cleft lip and cleft palate from the cleft hospital Gujrat Pakistan. Inclusion criteria include care givers (father, mother, grandmother, grandfather, and siblings) of children with cleft lip and cleft palate before surgery. Exclusion criteria include the care givers of children with other facial deformities or physical disabilities and caregivers who are relatives and friends. Uneducated individuals were 39 (19.5%), with middle education were 25 (12.5%), with primary education were 29(14.5%), with matriculation were 60 (30%), with intermediate were 15 (7.5%), with graduation were 19 (9.5%), and with masters education and above were 13 (6.5%).

25.5% individuals were residents in urban and 74.5% individuals were from different villages. 90.5 % participants from joint family system and 9.5 % from nuclear family system.

Caregiver Social Isolation Scale has 48 items and two factors - lack of social cohesion and mental agony, with 0 to 3 likert scale scoring categories, zero means never and three means always. Total score ranged from 0 to 144, higher the score; stronger is the experience of social isolation (Shafiq, & Anwaar-ul-Mustafa, 2022). DASS-21 is used for the evaluation of emotional distress in terms of depression, anxiety and stress. The rating ranged from 0 that is “did not apply to me” to 3 that is “apply to me very much” with total score range 0 to 63. Higher the scores, higher will be the level of depression, anxiety, and stress (Lovibond, & Lovibond, 1995). PWS has been measured by 18 items. The scoring categories ranged from 1 (strongly disagree) to 7 (strongly agree). However, items 1, 2, 3, 8, 9, 11, Q12, 13, 17, and 18 are reverse-scored. The total score ranged 18-126. Higher scores mean higher levels of psychological well-being (Boztepe, Çınar, & Özgür, 2020).

Informed consent and demographic sheets were taken before administration of scales. Assurance in verbal and written form was given to the clients that all the information’s provided by them will be kept confidential and they have the right to leave their participation at any stage. The information’s related to the purpose of research were also provided to them. All the instructions about solving the questionnaire were given to the participants. At the ends participants were admired for giving their precious time. Three scales were used for data collection as mentioned above. Written permission was taken from the authors and translators of the scales were taken. The data was analysed in SPSS-24 for correlations and reliabilities. However, mediation model with path analysis was tested in AMOS-24.

RESULTS

The Cronbach Alpha Reliability Coefficient showed that the Urdu versions of the standardized scales have satisfactory values between .83 to .97 (Table 1). The Pearson Product Moment Correlation Coefficients between variables and subscales of the variables showed significant relationship with each other. Social Isolation has positive significant relationship with depression ($r=.82, p<.01$), anxiety ($r=.78, p<.001$), stress ($r=.98, p<.001$), and negative significant relationship with well-being ($r= -.68, p<.001$) (Table 2). Thus, confirmed the conduction of path analysis to explore mediating role of caregiver social isolation between their emotional distress and wellbeing in relation to their children with cleft lip and cleft palate. Path analysis showed that caregiver social isolation ($\beta = -0.22, p < 0.01$) has partially and significantly mediated between wellbeing and their experiences of emotional distress in depression ($\beta = 2.45, p < 0.01$). However, with stress ($\beta = 1.10, p < 0.11$) and anxiety ($\beta = 1.97, p < 0.06$) in relation to wellbeing, the mediation is fully significant (Figure 1).

Table No. 1: Reliability Analysis of Scales (N=200)

Variables	No .of items	Alpha (α)
Caregiver Social Isolation	48	.97
Depression	07	.91
Anxiety	07	.83
Stress	07	.88
Wellbeing	18	.85

Table No. 2: Inter-Correlations among Study Variables (N=200)

Variables	M	SD	D	A	S	Wellbeing
CSIS	58.38	22.49	.82**	.78**	.78**	-.68**
D	8.14	3.95	-	.80**	.86**	-.67**
A	6.37	3.39		-	.79**	-.63**
S	8.70	3.53			-	-.58**
Wellbeing	60.57	12.96				-

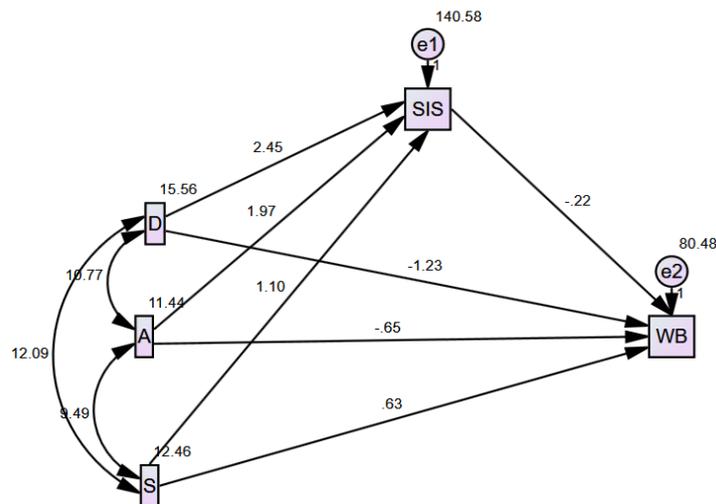


Figure 1: Mediating Role of Social Isolation (M) in Caregivers with Emotional Distress (X) and Wellbeing (Y)

DISCUSSION

This research aimed to find the verification of primary hypothesis of the study stated as there would be significant positive relationship between emotional distress and social isolation in caregivers of children with cleft lip and cleft palate. The results showed that there is a significant positive relationship among depression, anxiety, stress and social isolation in caregivers, confirming the hypothesis (Table II). This finding is consistent with the findings of the previous researches. The mothers who have children with cleft and cleft palate have high level of anxiety as compare to those mothers who have healthy children or children without any craniofacial problems. These mothers have less backing up from others while they faced high tension and stress due to congenital anomaly in their children (Johns, Hershfield, Seifu, & Haynes, 2018). The postpartum depression in the mothers of children with cleft lip and cleft palate, showed that 68% of them reported self-blame, 59% of them reported difficulty in coping, and 57% reported anxiety (Kumar, Kumar, Mehrotra, Gupta, Khandpur, Mishra, 2020).

The second hypothesis stated negative relationship between emotional distress and wellbeing in caregivers of children with cleft lip and cleft palate. The hypothesis is confirmed by the findings of the present study which are also been reported by the past researches. Depression, anxiety and stress influenced their subjective wellbeing detrimentally (De Cuyper, Dochy, De Leenheer, & Van Hoecke, 2019; Feragen, Myhre, & Stock, 2022). Caregiver's life quality or else their sense of wellness and mental health were affected due to limitation in information (Awoyale, Onajole, Ogunnowo, Adeyemo, Wanyonyi, Butali, 2016). The third hypothesis stated that higher the level of social isolation, lower would be their wellbeing. Past researches have showed similar findings. Social isolation and wellbeing are empirically found to have reciprocal relationship, with increase in level of social isolation, individuals have perceived their wellbeing poorly (Clair, Gordon, Kroon, Reilly, 2021; Lukács, 2021; Fernandez-Rio, Cecchini, Mendez-Gimenez, Carriedo, 2021; Issa, & Jaleel, 2021).

The fourth hypothesis that investigates social isolation s mediator between emotional distress and wellbeing in caregivers of children with cleft lip and cleft palate has also been confirmed by the results of the present study. The three distinct emotional distress states have differential impact on seclusion experiences of the caregivers from others. Depression is dynamically associated with isolation experiences as individuals withdraw and become introvert in seeking help from family and friends due to gloomy and sad mood with lack of interest in activities (Taylor, Taylor, Nguyen, Chatters, 2018; Santini, Jose, Cornwell, Koyanagi, Nielsen, Hinrichsen, Meilstrup, Madsen, Koushede, 2020; Elmer, & Stadtfeld, 2020). On contrary, the anxious and stressed out mental states work according to stress-buffer hypothesis that sense a presence of support from significant others, thereby boosting state of wellness and quality of life (Cohen, & McKay, 1984).. Therefore, the depressive mental state of caregivers mediates with isolation and partially strengthens the detachment element in their wellbeing by negative influences. In other words, higher the depression, stronger is the isolation, and poorer is

their wellbeing. But the presence of significant others with provision of assistance is neglected by caregivers due to depressed mental state.

Thus, the findings of the present study implied that caregivers of children with cleft lip and cleft palate are having relatives close to them to console but they do not perceive their availability due to depressed psychological mode and subsequent social isolation. Thus, mediation model explains insignificant direct impact of anxiety and stress on their wellbeing. However, subjective experience of loneliness or detachment or more precisely isolation has fully weakened their psychological wellbeing. Interventions to improve wellbeing through increase in social support, and reduction in distress and isolation have to focus on dyadic guardians.

CONCLUSION

Caregiver experiences of social isolation have partially mediated with depression to reduce their wellbeing. However, the former has completely mediated for anxiety-stress continuum with wellbeing, confirming stress-buffering effect and depression oriented withdrawal and back out in guardians of children with cleft lip and cleft palate. Implications highlighted need for clinical psychologists and psychologists to counsel and intervene with therapeutic programs to enhance wellbeing by reducing emotional distress and subsequent subjective isolation from others.

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REFERENCES

- Awoyale, T., Onajole, A. T., Ogunnowo, B. E., Adeyemo, W. L., Wanyonyi, K. L., & Butali, A. (2016). Quality of life of family caregivers of children with orofacial clefts in Nigeria: a mixed-method study. *Oral diseases*, 22(2), 116-122.
- Boztepe, H., Çınar, S., & Özgür, MD, F. F. (2020). Parenting stress in Turkish mothers of infants with cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*, 57(6), 753-761.
- Carvalho, N. O., Matos, M. F. S., Belchior, I. F. C., Araújo, M. B., Rocha, C. T., & Neves, B. G. (2021). Parents' Emotional and Social Experiences of Caring a Child with Cleft Lip and/or Palate. *Pesquisa Brasileira em Odontopediatria e Clínica Integrada*, 21: e0168.
- Clair, R., Gordon, M., Kroon, M., & Reilly, C. (2021). The effects of social isolation on well-being and life satisfaction during pandemic. *Humanities and Social Sciences Communications*, 8(1), 1-6.
- Cohen, S., & McKay, G. (2020). Social support, stress and the buffering hypothesis: A theoretical analysis. In *Handbook of psychology and health (Volume IV)* (pp. 253-267). HJ: Hillsdale: Routledge
- De Cuyper, E., Dochy, F., De Leenheer, E., & Van Hoecke, H. (2019). The impact of cleft lip and/or palate on parental quality of life: a pilot study. *International Journal of Pediatric Otorhinolaryngology*, 126, 109598.
- Elmer, T., & Stadtfeld, C. (2020). Depressive symptoms are associated with social isolation in face-to-face interaction networks. *Scientific reports*, 10(1), 1-12.
- Feragen, K. J. B., Myhre, A., & Stock, N. M. (2022). "Will You Still Feel Beautiful When You Find Out You Are Different?": Parents' Experiences, Reflections, and Appearance-Focused Conversations About Their Child's Visible Difference. *Qualitative health research*, 32(1), 3-15.
- Fernandez-Rio, J., Cecchini, J. A., Mendez-Gimenez, A., & Carriedo, A. (2022). Mental well-being profiles and physical activity in times of social isolation by the COVID-19: a latent class analysis. *International Journal of Sport and Exercise Psychology*, 20(2), 436-450.
- Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.
- Issa, H., & Jaleel, E. (2021). Social isolation and psychological wellbeing: lessons from Covid-19. *Management Science Letters*, 11(2), 609-618.
- Johansson, B., & Ringsberg, K. C. (2004). Parents' experiences of having a child with cleft lip and palate. *Journal of advanced nursing*, 47(2), 165-173.
- Johns, A. L., Hershfield, J. A., Seifu, N. M., & Haynes, K. A. (2018). Postpartum depression in mothers of infants with cleft lip and/or palate. *Journal of Craniofacial Surgery*, 29(4), e354-e358

- Kumar, K., Kumar, S., Mehrotra, D., Gupta, S., Khandpur, S., & Mishra, R. K. (2020). A psychologic assessment of the parents of patients with cleft lip and palate. *Journal of Craniofacial Surgery*, 31(1), 58-61.
- Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour research and therapy*, 33(3), 335-343. doi: 10.1016/0005-7967(94)00075-U.
- Lukács, A. (2021). Mental well-being of university students in social isolation. *European Journal of Health Psychology*, 28(1), 22-29.
- Martelli, D. R. B., Coletta, R. D., Oliveira, E. A., Swerts, M. S. O., Rodrigues, L. A. M., Oliveira, M. C., & Martelli Júnior, H. (2015). Association between maternal smoking, gender, and cleft lip and palate. *Brazilian journal of otorhinolaryngology*, 81, 514-519.
- Mirowsky, J., & Ross, C. E. (2002). Measurement for a human science. *Journal of health and social behavior*, 152-170.
- Razera, A. P. R., Trettene, A. D. S., Tabaquim, M. D. L. M., & Niquerito, A. V. (2017). Study of burden among caregivers of children with cleft lip and palate. *Paidéia (Ribeirão Preto)*, 27, 247-254.
- Ryff, C. D. (1995). Psychological well-being in adult life. *Current directions in psychological science*, 4(4), 99-104.
- Santini, Z. I., Jose, P. E., Cornwell, E. Y., Koyanagi, A., Nielsen, L., Hinrichsen, C., ... & Koushede, V. (2020). Social disconnectedness, perceived isolation, and symptoms of depression and anxiety among older Americans (NSHAP): a longitudinal mediation analysis. *The Lancet Public Health*, 5(1), e62-e70.
- Shafiq, S., & Anwaar-ul-Mustafa, M. (2022). Development and validation of Caregiver Social Isolation scale. PAFMJ.
- Sharif, F., Mahmood, F., Azhar, M. J., Asif, A., Zahid, M., Muhammad, N., ... & Neil, S. M. (2019). Incidence and management of cleft lip and palate in Pakistan. *J Pak Med Associat*, 69(5), 632-39.
- Taylor, H. O., Taylor, R. J., Nguyen, A. W., & Chatters, L. (2018). Social isolation, depression, and psychological distress among older adults. *Journal of aging and health*, 30(2), 229-246
- Zavaleta, D., Samuel, K., & Mills, C. T. (2017). Measures of social isolation. *Social Indicators Research*, 131(1), 367-391.