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A Phenomenological Study to Assess the Lived Experiences of Parents of Children with Congenital Disorders Admitted in Paediatric Health Care Settings of Selected Paediatric Hospitals, Vadodara

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Abstract---

Background: *Congenital anomalies have been understood as a root cause for neonatal morbidity and mortality in recent days. Living with congenital anomaly is a critical issue and that might influence diverse aspects of parent's life. It is a burden for the parents, to deal with hospitalization and activities of daily living of the children.*

Aim*: The investigators aimed to illustrate the lived experiences of parents having children with congenital anomalies.*

Material and Methods: *A qualitative study was carried out using phenomenological hermeneutical method to transcribe the lived experiences of the parents having children diagnosed with any form of congenital anomaly. Twenty five mothers were identified from three pediatric hospitals by convenience sampling technique and interviewed by using open ended questionnaire. Each interview was audio recorded and lasted for 30 to 45 minutes. The narrated experiences were interpreted into a meaningful statement for exploration. The analysis of collected information lead to development of themes.*

Results: *The present study helped us to highlight the emotions, feelings and challenges of parents dealing with children during their hospitalization. Socio-demographic characteristics shown that majority (84%) of the parents were mothers. The interview verbatim was transcribed into seven themes for deeper understanding. (1) Emotional experiences (2) Experiences related to Financial issues (3) Experiences concerned to Social perspectives (4) Child centered experiences (5) Experiences on knowledge and awareness (6) Child self care experiences (7) Experiences towards exposure to unfamiliar environment.*

Conclusion: *The study insists the importance of routine assessments to be conducted by the health care providers to understand the strange experiences of parents during their child's hospitalization. The support they*

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receive through health care and therapeutic interpersonal relationship would promote the physical and psychological well being of parents.

Keywords--- *Congenital Anomalies, Lived Experiences, Parents, Hospitalization.*

I. INTRODUCTION

Gestation is a period of conversion in the life of the woman in which, from the time of fertilization until birth, the pregnant woman and the baby pass through exceptional psychological, physiological and social experiences, causing the woman to have doubts and expectations in relation to the new being that is yet to be born and to the role she will have to assume. It can also lead both the parents to feelings of anxiety, and frustration if the couples are expecting for the first baby[1-2]. According to the latest WHO data published in 2017 Congenital Anomalies Deaths in India reached 116,118 or 1.32% of total deaths. The age adjusted Death Rate is 8.33 per 100,000 of population ranks India in the world[3].

The leading causes of infant morbidity and mortality in poorer countries are malnutrition and infections, whereas in developed countries they are cancer, accidents and congenital malformations. Congenital anomalies account for 8–15% of perinatal deaths and 13–16% of neonatal deaths in India. Patients with multiple congenital anomalies present a relatively infrequent but tremendously difficult challenge to the pediatrician. The proportion of perinatal deaths due to congenital malformations is increasing as a result of reduction of mortality due to other causes owing to the improvement in perinatal and neonatal care[4-5].

Anxiety, fear, panic and knowledge deficit are the major problems and experiences of the parents who have children with congenital anomalies. When the malformation is mismatched with life, the situation can lead to great distress and implications for the parents, family members and other relatives, bringing feelings of frustration, guilt, disability and loss, crises in the family system and social isolation[6].

II. MATERIAL & METHODS

For the purpose of conducting the present study, we adopted a phenomenological hermeneutical method to transcribe the lived experiences of parents having children with congenital anomalies. We chose this method in order to get deeper understanding of lived experiences of parents. We used non probability convenience sampling technique to recruit 25 parents from three paediatric hospitals where children treated for congenital anomalies. Participants met the inclusion criteria of sampling technique such as willingness to participate in the study and prepared to extend cooperation throughout the interview were added into the study. Prior to data collection the purpose of the study was explained and obtained written consent from the study participants. The tool was validated by the experts for its feasibility and convenience. The investigators conducted in-persons interview for data collection. At the onset demographic characteristics of the respondents was recorded and followed by open ended structured questionnaire was administered to collect information on lived experiences. The advantage of the open ended questionnaire was to allow the respondents to explore their experiences without any limitations. Each interview was audio recorded and lasted for 30-45 minutes. Participants were asked to express their lived experiences on their regional, mother language. The interview was transcribed word by word and filed. The

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investigators done read and re-reading of the narrations for deeper understanding and after discussion among the investigators, it was concluded with seven themes. The demographic data of the respondents was analysed by descriptive statistics (Frequency and percentage).

III. FINDINGS

Socio-demographic characteristics of the respondents: Total of 25 parents was assessed and almost 64% of the mothers were less than 30 years old. Most of the participants were (84%) women. Illiterate parents were found to be (76%). Out of 25 parents, none had a history of previous baby with congenital anomaly. Majority (76%) of the participants had their children hospitalized less than a month.

n=25

S.NO	Variables		Frequency	Percentage
1	Age of the parents	>30 years	9	36%
		<30 years	16	64%
2	Parental role	Father	4	16%
		Mother	21	84%
3	Level of education	Illiterate	19	76%
		Primary	3	12%
		Secondary	2	8%
		Graduate	1	4%
4	Other children in family	Yes	12	48%
		No	13	52%
5	Previous pregnancy with congenital anomalies	Yes	0	0
		No	25	100%
6	Average days of Hospitalization	>1 month	6	24%
		<1 month	19	76%

Hermeneutic phenomenological interpretation of lived experiences: From analysis of the interview seven themes were emerged (1) Emotional experiences (2) Experiences related to Financial issues (3) Experiences concerned to Social perspectives (4) Parental Child centered experiences (5) Experiences regarding knowledge and awareness (6) Child self care experiences (7) Experiences towards exposure to unfamiliar environment.

Emotional Experiences

All participants expressed an initial feeling of fear and panic by knowing that the child is diagnosed with congenital anomaly. Parental emotional stress was observed throughout the interviews. Most of the parents were found restlessness and emotionally exhausted. Quotations that illustrate this theme as "*I feel bad and I was shocked….I was tensed, cried a lot and was heartbroken….All my family members went on grief….*"

Experiences Related to Financial Issues

Another common theme found among the participants was the experience of financial struggle. Several parents had expressed their uneven economical stability and financial status. Parents had gone through extreme struggles to manage the current disease course of their children. Financial management experiences of the parents were narrated as "*We are financially poor, so we had borrowed money from other family members, relatives, and friends….I don't know anything how to manage so friends helped me….We took instant gold loan to manage the hospital expenses*"

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Experiences Concerned to Social Perspectives

Almost as a consequence of congenital anomaly in children, parents expressed the experience they faced in the society. It is the great pain that evoked by the perspectives of the society one belongs to during tough times. The whole family witnessed the limitations the disease imposed on the child's socialization and the impact of social integration during the disease process…. "*Society always feels pity on that affected child…Parents feel negligence of themselves to having congenital disorder child…My child is not willing to play with his peer group…..Perception of the society changes according to disease pattern"*

Parental Child Centred Experiences

Another theme emerged was the feelings of parents who witnessed the problem for the first time towards their children future perspectives. The motherhood is the ultimate sufferer in any disease course in the family. They have to tolerate several difficulties along with their routine social roles. Performing roles like caring the children and other family members, doing a job, domestic day today routines indicates that the mother is experiencing intolerable pain throughout life time. Many mothers told us, "*We are tensed about future life/marriage of the child….Society tries to suppress their emotion and try to feel them embraced and shame…We are worried that how my child will cope up with the disability in future.."*

Child Self Care Experiences

Self care is the ability to perform the day to day activities on one's own. The affected child becomes dependent either temporarily or for life time. It affects the quality of life of the children and makes the future of the child unpredictable…."*Child with congenital disorder doesn't get same knowledge similar to normal child….I predict that my child may have Developmental delay in near future….My child is going to be dependent throughout his lifetime.."*

Experiences Regarding Knowledge and Awareness

The theme which has got major focus was regarding the cognition of the Parents. They verbalized that had lack of knowledge and awareness in terms of disease and management protocols. They were extremely worried and curious to know about the unknown facts of the illness. Parents narrated as "*We are having problem to communicate with staffs and doctors….We didn't know about treatment and hospitalization….We became panic when listened to the medical terminologies"*

Experiences Towards Exposure to Unfamiliar Environment

The theme that emerged for the Parents freshly entered into the hospital reported their experiences about unfamiliar hospital environment during their child's hospitalization. It was found strange to uneasy and sometimes annoying for the parents due to movements through various unfamiliar health care areas. *Too much crowded hospital….We didn't know anything about OPD, ward, department, specialist, treatment, staff, doctors, expenses etc…We felt entered into strange world"*

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IV. DISCUSSION

The purpose of this study was to interpret the lived experiences of parents having children with congenital anomalies. Study has concentrated on the verbatim narrations and developed seven themes. The investigators found the parents were facing experiences on various aspects concerned with the disease process of the children. Most of the parents reported about their financial crisis and exposure to unfamiliar health care settings for the first time. The study findings match with the similar type of study conducted by ***Gatford A*** on mothers experience regarding Down syndrome from different cultures. They demonstrated their comparative isolation and the influence of cultural beliefs, and also that despite much research and study there is still a lack of respect and value in the way they had been treated[7].

Emotional experiences of the parents were noted several times and similar findings were mentioned in a qualitative study conducted by ***O'Connell*** on maternal experience of congenital anomaly during prenatal period also found that deep sense of loss and sadness among the mothers[8]. A profoundly emotional journey indicated the grieving process of parents in the current study too. In support of the study results explored by ***Bruce E***, in 2016, on lived experiences of fathers regarding congenital heart defects, it was clearly understood that family support during health crisis in the family[9]. The present study also revealed the experiences narrated by the parents in terms of lack of support.

Child centered care or family centered care is the core aspect of disease management process. The present study explored the experiences of parents regarding child care perspectives which are correlated with the study results revealed by ***Sundin K*** in 2014 on mothers of children with congenital heart diseases[10]. Experience on disclosure of the disease pattern or diagnosis would lead to positive or negative mindset of the children and parents. The investigators found that the children were informed and aware about their ill health status with less or serious impact on emotions. The parents were extremely worried and despair. ***Goodwin J et al*** also suggests that disclosing the secrets regarding health issues lead to positive or negative impact on psychological well being of parents and children[11].

Congenital anomaly like Spina bifida influences the child and parents negatively in terms of their physical and mental health. In the present study several parents narrated about the future challenges of the child ranging from self care issues to personal life. ***Nahal MS*** et.al has also mentioned in their study regarding the parent's negative self concept and experiencing vulnerability due to congenital anomaly[12].

The present study explored the stress of the parents during their child's hospitalization. These findings were in line with the study conducted by **Cantwell-Bartl AM** et.al shows that the study participants had experienced extreme stress[13]. **Goodwin J et al** also found that hospitalization and disease process affects the relationship between the parent and child[14].

V. CONCLUSION

The hermeneutic interpretation of the present qualitative study revealed the parents lived experiences in terms of emotions, feelings, societal perspectives and child care issues. The study findings could be used in education of staff

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nurse and other health care professionals to promote understanding the experiences and the best way to help them. Therapeutic nurse patient relationship plays a vital role in reducing such emotional burden of the parents especially when children are hospitalized. Health care providers have to be prepared not only to treat the patients but also to provide family centered and person centered care in every situation.

Ethical Clearance

The study was conducted after obtaining written consent from the participants and approval from the institutional ethics committee.

Conflict of Interests

The author declares that there is no conflict of interest to disclose.

Source of Funding

The researcher didn't receive any funding from other sources and declares that this is a researcher's self funded project.

REFERENCES

[1] Cunha AC, Pereira JP, Jr, Caldeira CL, Carneiro VM. Diagnosis of congenital malformations Impact on the mental health of pregnant women. *Estud Psicol.* 2016; 33(4):601–611.
[2] Hammonds M. Linking early healthy attachment with long-term mental health. *Nurs N Z.* 2012;18(2):12–14
[3] JASIM, WISAM ABDULLAH, and HUSSEIN IMRAN MOUSA. "NEUROSURGICAL CONGENITAL ANOMALIES IN BASRAH SOCIODEMOGRAPHIC REVIEW." *International Journal of Medicine and Pharmaceutical Science (IJMPS* (8.2), Apr 2018, 33-38
[4] https://www.worldlifeexpectancy.com/india-congenital-anomalies
[5] Bhat BV, Ravikumara M. Perinatal mortality in India-Need for introspection. *Indian J Matern Child Health.* 1996;7:31–3.
[6] NEELAM, THAKUR. "AN EPIDEMIOLOGICAL STUDY OF MENTAL RETARDATION WITHOUT A COMMON GENETIC CAUSE, IN THE POPULATION OF HIMACHAL PRADESH, INDIA." *International Journal of Environment, Ecology, Family and Urban Studies (IJEEFUS)* (7.5,) Oct 2017, 23-32
[7] Agarwal SS, Singh U, Singh PS, Singh SS, Das V, Sharma A, et al. Prevalence and spectrum of congenital malformations in a prospective study at a teaching hospital. *Indian J Med Res.* 1991; 94: 413–9.
[8] RADHIKA, RANI L., and S. CHANDRALINGAM. "ACOUSTIC ANALYSIS OF CRY SIGNAL TO DIFFERENTIATE HEALTHY AND CONGENITAL HEART DISORDER IN INFANTS." *International Journal of Electronics and Communication Engineering (IJECE)* (5.6), Oct - Nov 2016; 21-28
[9] Santos MM, Böing E, Oliveira ZA, Crepaldi MA. Prenatal diagnosis of malformations incompatible with life: psychological implications and possibilities of intervention. *Rev Psicol Saúde.* 2014;6(1):64–73
[10] GIRI, RANJANA, et al. "GIANT CONGENITAL NEVUS WITH PLEXIFORM NEUROFIBROMA AND EPITHELOID VARIANT OF MALIGNANT PERIPHERAL NERVE SHEATH TUMOR WITH MELANOCYTIC DIFFERENTIATION A RARE CASE REPORT." *International Journal of General Medicine and Pharmacy (IJGMP* (4. 2) Mar 2015, 81-86
[11] Gatford A Down's syndrome: experiences of mothers from different cultures *Br J Nurs.* 2001 Oct 11-24; 10(18):1193-9.
[12] O'Connell O[1], Meaney S[2], O'Donoghue K, Anencephaly; the maternal experience of continuing with the pregnancy. *Incompatible with life but not with love Midwifery* 2019 Apr; 71: 12-18.
[13] Bruce E, Lindh V, Sundin K, Support for Fathers of Children With Heart Defects, *Clin Nurs Res.* 2016 Jun;25(3):254-72.
[14] Bruce E, Lilja C, Sundin K, Mothers' lived experiences of support when living with young children with congenital heart defects, *J Spec Pediatr Nurs.* 2014 Jan; 19(1):54-67.

DOI: 10.37200/IJPR/V24I5/PR2020709
Received: 18 Apr 2020 | Revised: 26 Apr 2020 | Accepted: 16 May 2020

[15] Montano-Soto, Tatiana, Evarista Arellano-García, and L. Camarena-Ojinaga. "Genotoxic biomonitoring and exposure to pesticides in women laborers at maneadero valley in Baja California, Mexico." *International Journal of Applied and Natural Sciences* 3.2 (2014): 89-96.

[16] Goodwin, J., Schoch, K., Shashi, V., Hooper, S. R., Morad, O., Zalevsky, M., Gothelf, D., & Campbell, L. E. (2015). A tale worth telling: the impact of the diagnosis experience on disclosure of genetic disorders. *Journal of intellectual disability research: JIDR,* 59(5), 474–486.

[17] Nahal MS, Axelsson ÅB, Imam A, Wigert H, Palestinian children's narratives about living with spina bifida: Stigma, vulnerability, and social exclusion, *Child Care Health Dev.* 2019 Jan;45(1):54-62.

[18] Atoum, Maysoun, and Mahmoud Alhussami. "EXPLORATION OF THE MENTAL HEALTH NEEDS AND SERVICES FOR ADOLESCENTS: A QUALITATIVE STUDY." *International Journal of Applied and Natural Sciences (IJANS)* (7.3) Apr - May 2018; 73-88

[19] Cantwell-Bartl AM, Tibballs J Parenting a child at home with hypoplastic left heart syndrome: experiences of commitment, of stress, and of love Cardiol Young. 2017 Sep;27(7):1341-1348.

[20] Goodwin J, Swaab L, Campbell LE, She'll be able to live independently… as long as I'm around": The "lived" experience of parenting a child with 22q11.2 deletion syndrome in the transition to adulthood. *J Appl Res Intellect Disabil,* 2020 Jan 9.

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