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Aims and Scope of Indian Journal of Developmental and Behavioural Pediatrics (IJDBP)

IJDBP is a specialty journal in Developmental and Behavioural pediatrics published by Indian Academy of Pediatrics Chapter of Neurodevelopmental Paediatrics

The Journal welcomes Original papers, Review articles, Case reports and other articles relevant to child development & Behaviour including :

- Neuro developmental disorders,
- Developmental delays,
- Behavioural issues,
- Autism,
- Attention deficit hyperactivity disorder,
- Learning difficulties,
- Intellectual disabilities,
- Evidence based role of early intervention,
- Family centred multidisciplinary intervention,
- Neurogenetic disorders affecting child development,
- Neuroimaging & Neurological issues affecting child development,
- Corrective and assistive surgeries
- Home environmental and environmental issues affecting child development,
- Medical conditions
- Low birth weight and High-risk neonate requiring neonatal intensive care & its outcome,
- Preventive aspects in adolescents and pregnancy.
- Management of conditions covered in Rights of Persons with Disability Act,2016 of GOI.

It aim to promote advances in research in the field of child development and Behavioural issues so that latest evidenced based information is shared to enhance the quality of care and improve lives of children with special needs and their families.

The journal will be National Double Blind Peer review Open access journal published Quarterly. We will accept for publication manuscripts that were not published earlier in any form. The journal is devoted to publishing quality papers based on original innovative and most advance research in the field of developmental behavioural pediatrics.

The Journal aims to have the highest possible ethical and publication standards by scrutinizing the papers, through peer review assisted by eminent experts from prestigious teaching institutes from the country. For all Manuscripts submitted the journal will employ a plagiarism detection system for detecting plagiarism against previously published work.

VISION STATEMENT

As a grassroots Pediatrician specialising in intensive care but working equally in general paediatrics in a major town in central India, along with my wife who is a devoted obstetrician, we had the opportunity to care for hundreds of babies who were considered 'high risk'. Our hearts went out to these children- often these were precious children and parents were more emotionally attached to them than otherwise. As we saw these children grow, we were used to dealing with post NICU care, then ROP, hearing loss, tone and motor abnormalities, motor and global delay, intellectual disabilities and cerebral palsy. Helping these children develop was our priority. Over the last decade or two, the scenario has changed. In addition to the above concerns, we started seeing larger number of children who were not high risk at birth, but presented with developmental and behavioural concerns. Children who spoke late or children who were hyperactive.

We started seeing more children with academic concerns. ADHD, Autism and Learning difficulties became common parlance. Hoever, in the post-Covid era, we now have a surge of behavioural concerns from infants to adolescents. The level of hyperactivity, irritability, anxiety and depression has gone to another level. The challenge paediatricians find themselves facing is summated by this change in epidemiology. From early diagnosis to intervention, from counselling to monitoring, paediatricians are faced with incorporating these elements into their practice. The Indian Academy of Pediatrics has accepted the challenge of bringing forty four thousand paediatricians up to date with this daunting task.

The IAP Nurturing Care Early Childhood Development Program is one of the world's largest and most pervasive programs on ECD – more than 6000 pediatricians have been trained in a short period of 18 months. Innumerable workshops on various aspects of developmental behavioural paediatrics and adolescence have been carried out across the country.

As the President Elect 2024, I hereby reiterate the Academy's commitment to this magnificent task. I am sure with the support of our academicians and publications like the Indian Journal of Developmenatl Behavioural Pediatrics we will be able to rise up to the task.

Dr Vasant Khalatkar (MD)
IAP National President elect24

VISION STATEMENT PATRON- 2024

Optimising developmental and behavioral screening in the Indian context-if not now-when…

Child development is the prime domain of Pediatrics. Thus the field of Developmental Behavioral Pediatrics is indeed the spine of mainstream Pediatric practice. As infections wane the focus on preventive and social pediatrics will regain.

Developmental surveillance, screening are probably the key words in Developmental Pediatrics. Universal surveillance, better screening and assessments with the right and best intervention practices can lead us to improved functional outcomes. Awareness and training in this direction should lead us to the goals of reduction in disability due to the neurodevelopmental disorders.

Surveillance- elicitation of developmental concerns at routine Pediatric OPD visits ideally accompanied with documentation of the developmental history with risk factors and recommendations.

Screening- includes the use of standardized validated tools at specific defined ages or when developmental concerns are reported to identify delays.

The domain of development is incomplete without the inclusion of behavior. The awareness of typical and atypical patterns of age appropriate behaviors is an aspect that is often neglected in Pediatrics and may thus lead to missing of important clues leading to solving developmental problems.

Thus good surveillance and screening results in early identification of developmental delays and behavioral problems paving the way to right and timely intervention.

The property of neuroplasticity underlies the whole concept of early intervention in developmental and behavioral problems. Neuroplasticity is the ability of the brain to adapt in response to stimuli, both internal and external and reorganize its networks structurally and resultantly functionally. The beneficial aspect of neuroplasticity can be used to promote and learn developmentally appropriate goals in children with delayed or deviant development. It is a well-known fact that stimulation and intervention with early and developmentally appropriate experiences can optimize outcomes and improve developmental trajectories.

As Jean Piaget quoted –"Experience precedes understanding".

The IJDBP journal dedicated to this field in the Indian context can sow the seeds to enrich our knowledge further and add to better proven hypotheses in the future to guide screening and intervention practices in our indigenous cultural context.

Warm regards,

Dr Leena Srivastava
National Chairperson, IAP Chapter of Neurodevelopmental Pediatrics
Head, Developmental and Behavioral Pediatric unit,
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INVITED GUEST EDITOR

Embracing Diversity and Building Inclusive Communities: A Call to Action for Child With Special Needs

As we come together in the pages of the Indian Journal of Behavioural & Developmental Pediatrics, it is imperative to reflect on the progress we have made in the field and the journey that lies ahead. Children with Special Needs is not just a medical condition; it is a life experience that encompasses the physical, emotional, and social aspects of a child's life. In this guest editorial, we call for a renewed commitment to embracing diversity and building inclusive communities for these special children.

Children with Special Needs are a diverse group, each with their unique strengths, challenges, and dreams. Our first call to action is to recognize and celebrate this diversity. No single approach or intervention can fully address the needs of all these children. Instead, we must promote personalized, family-centered care and support that respects the individuality of each child.

Inclusivity is not just a buzzword; it is a foundational principle that should guide our work. Inclusive education, for instance, is a powerful tool in creating opportunities for all these children to thrive. We must advocate for policies and practices that ensure every child, regardless of their abilities, can access quality education in mainstream settings. Inclusivity should extend beyond the classroom and into extracurricular activities, healthcare, and all aspects of life

Moreover, fostering inclusivity requires the active participation of communities, families, and policymakers. It is essential to engage in dialogue and collaborate with all stakeholders. We must promote awareness, dispel myths and misconceptions, and advocate for equal rights and opportunities for children. By doing so, we can break down barriers and reduce stigma.

Research in childhood disability is pivotal. We need to invest in innovative studies that address pressing questions related to the well-being of differently abled children. This research should inform evidence-based interventions, therapies, and policies that promote their holistic development and improve their quality of life.

As we navigate the challenges and opportunities in the field of childhood neurodevelopment, let us remember the strength, resilience, and potential that these children possess. They are not defined by their handicaps but by their dreams, aspirations, and the support systems that surround them.

In conclusion, this journal should serves as a platform to share knowledge, insights, and experiences that can drive positive change for children with special needs. We, as a community, have a collective responsibility to create a more inclusive and welcoming world for them. Our commitment to diversity and inclusivity is not just a professional obligation but a moral imperative.

Let us work together to build a future where all children, regardless of their abilities, can lead happy, fulfilling lives. Together, we can turn dreams into realities, to build a future where all children, regardless of their abilities, can lead happy, fulfilling lives.

Warm regards,

Dr. Jeeson Unni (M.D.)
Advisor, IJDBP

EDITORIAL

Season's Greetings. Climate change has far-reaching consequences, and its impact on child development and behaviour is a growing concern. The changing climate introduces a range of health, environmental, social, and psychological stressors that can influence children in various ways.

Health Implications: Both Mental & Physical Health are affected. The stress of climate-related events, such as natural disasters, can contribute to mental health challenges in children. Anxiety, depression, and post-traumatic stress disorder are potential consequences. Extreme temperatures, heatwaves, and changes in disease patterns can affect physical well-being.

Environmental Disruptions & Displacement: Rising sea levels, extreme weather events, and resource scarcity may force families to migrate, leading to disruptions in children's lives. Frequent relocations can impact stability, education, and social relationships. Reduced biodiversity may limit opportunities for outdoor activities and connection with nature, impacting physical and emotional development.

Educational & Social Challenges: Climate-related events can lead to Disruptions in Education as a result of school closures, affecting children's access to education. Disrupted learning environments and frequent transitions can hinder cognitive development. Climate change can contribute to the spread of diseases, causing increased absenteeism due to illness, further impacting educational progress. Vulnerable populations, often children in low-income communities, are disproportionately affected by climate change. The resulting inequalities in resource distribution, healthcare, and opportunities can hinder children's social development.

Behavioural Changes: Children may develop adaptive behaviours in response to climate-related challenges. This could include changes in daily routines, altered play patterns, and increased awareness of environmental issues. Anxiety and Fear, Children exposed to climate-related events or messages may experience heightened anxiety and fear about the future. Concerns about the environment and uncertainty can impact their psychological well-being.

Addressing the impact of climate change on child development requires a comprehensive approach. This includes implementing policies to mitigate climate change, promoting sustainable practices, and providing support systems for families and communities. Additionally, educating children about climate change and empowering them to be advocates for environmental sustainability can contribute to positive behavioural changes and a more resilient future. We paediatricians as custodians of child health & well being need to be the ambassadors highlighting the impact of climate change on children health and holistic development. In line with this under leadership of our IAP National President Professor G.V. Basavaraja, IAP HSG Professor Yogesh Parekh, National Treasurer Dr Atanu Bhadra the Theme of our National conference (PEDICON 2024,Kochi) is "Global Warming & Child Health".

Happy to share that our Journal is now indexed in Index Copernicus & we will receive ICV (Index Copernicus Value) in October 2024. I thank my learned editorial board for this accomplishment.

Best Regards

Dr. Zafar Mahmood Meenai
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Editor-in-Chief, IJDBP

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Knowledge & Practice of Genetic Counseling in Developmental Disorders

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Genetic Counseling (GC):

The term "genetic counseling" was first coined in the USA in 1947 by Prof. Sheldon Reed & later he elaborated his views in his book- *Counseling in Medical Genetics*- in 1956[1]. However, the era of 'Genetic Counseling' as a separate profession began almost 4 decades later when a book on "Practical Genetic Counseling" was written by Peter Harper in 1981 and soon spread across the globe. The definition of genetic counseling (GC) has not much changed since then and is defined as "a communication process which deals with the special health service that provides information& support to the people who have or may be at risk of genetic disorders in a family". [2,3,4]

One of the primary goals of genetic counseling is to accurately diagnose the genetic condition by advising the patients on appropriate genetic investigations based on available genetic technology & approved methods. Secondly, to prevent the happening of genetic disorders or birth defects again in that family by explaining the means & ways of preventing the specific genetic disorder [5].Considering the burden of genetic disorders in India and often association with developmental disorders (DD), the significance of genetic counseling in their early detection & prevention cannot be ruled out[6]. The primary goal of genetic counseling in any developmentally delayed child is to accurately diagnose the genetic cause after dismissing the non-genetic factors such as postnatal infection, trauma, or any other environmental factors responsible for mental or motor delay.

Genetic Causes of Developmental Disorders:

Thus, the etiology of various developmental disorders, including **intellectual disability** (ID) and **autism spectrum disorders** (ASD) is heterogeneous. It could be genetic, non-genetic, or both and it is still unknown in about 40-50 % of cases. The various genetic causes such as chromosomal abnormalities (both numerical &structural), single gene or Mendelian disorders, metabolic disorders, mitochondrial disorders, repeat disorders, and imprinting disorders are recently well described in the literature as genetic causes[6]. The experienced clinician often arrives at the suspicion of a genetic factor underneath the developmental disorder and in consultation with a geneticist team member makes further recommendationsfor essential genetic or metabolic investigations. Accordingly, karyotype (basic chromosomal genetic test),or metabolic screening (if IEM is suspected) or high-resolution

cytogenetic microarray (if microdeletion or duplication syndromes are suspected or even in unknown ID), or Whole Exome or Whole Genome sequencing (in specific medical conditions like dysmorphism, unclassified congenital birth defects, epilepsy, or unclear and unknown clinical diagnosis)are recommended in a developmental disorder. The radiological (Brain MRI, EEG, NCV, etc.) and ultrasonography investigations are always used to support the genetic diagnosis. For example, a brain MRI in Glutaric aciduria type1 or in Maple Syrup Urine Disorder (MSUD) is very informative as an additional confirmation for the genetic diagnosis.

Genetic syndromes associated with developmental delay are easily diagnosed in a few cases due to well-characterized dysmorphic features, congenital birth defects, and phenotypically correlated biochemical, metabolic& chromosomal testing. The genomic studies confirm further the inheritance or *de novo*nature of transmission. A few chromosomal and ID syndromes are common in genetic practice and can be easily identified such as Down syndrome, Fragile-X syndrome, Di-George syndrome, or some neurogenetic condition such as Tuberous sclerosis. However, the referring clinician is not expected to be equipped with genetic knowledge to suspect or identify rare genetic syndromes. Hence, the help of a medical geneticist or trained genetic counselor at this juncture is very crucial. Genetic counseling offers advice and explains to parents/couples about the nature of genetic conditions& future pregnancy planning to prevent the recurrence risk.

Several genetic conditions cause global developmental delay (GDD) - both mental & motor- in a child. Developmental disabilities in neonates & children can be caused by a number of variables including genetic factors, infections during pregnancy, prematurity, birth complications, and the mother or child's exposure to environmental chemicals as well as the mother's health & lifestyle e.g. smoking & alcohol intake[7,8].It is important to differentiate between genetic & non-genetic factors causing the developmental delay.

The various genetic disorders involve congenital birth defects, inborn errors of metabolism (IEM), neurodegenerative and behavior disorders which often manifest various overlapping signs & symptoms. Intellectual disability, GDD, Autism Spectrum Disorders(ASD), and Learning disabilities fall in this category of developmental disorders. Varying proportions of ID cases (ranging from 17% to 50%) are attributed to genetic causes[6] with approximately 40% of the excess of boys, indicating X-linked genetic disorders. The majority (50- 60%) of ID cases will manifest comorbidities, like seizures, behavioural and psychiatric problems. ASD has recently emerged as a neurodevelopmental heterogenous group having increased incidence (1in 100 to 1 in 64 as per US census) and with varied genetic factors, including lifestyle or prenatal events or inheritance. The hearing & vision impairment can also be due to genetic factors leading to further mental delay, if not detected early. The ambiguous genitalia is another diagnostic sign of clinical importance.

To arrive at the precise genetic diagnosis for appropriate & easy genetic counseling, the expert genetic counselor takes the detailed birth & family history with documentation of **pedigree charting of 3 generations** to arrive at the inheritance pattern &understand the genetic factor[9]. For example-

❖ History like advanced maternal age, recurrent

pregnancy loss/stillbirths, increased carrier risk due to ethnic background, family history of birth defects or mental retardation& abnormal prenatal ultrasound findings.

- ❖ Children born with facial dysmorphism, mental retardation, congenital anomalies and mental/ motor deficiency and / global developmental delays will require certain genetic testing for diagnosis.
- ❖ In case of any severe mental/motor delay, spasticity, neuro-degeneration or neuro-regression and muscular weakness of primary muscles neurological and genetic evaluation will be necessary with additional supportive radiological or biochemical investigations.

In the case of a developmental disorder, the genetic counselor observesthe principles & practice of genetic counseling& works on the following main aspects [10]

1. Diagnostic and clinical aspects of a developmental disorder
2. Documentation of family and pedigree information of the affected patient
3. Recognition of inheritance patterns & risk estimation of the identified genetic condition
4. Communication and empathytowards the parents/affected family
5. Information on available options & further measures in the patient
6. Support in decision-making/decisions made by the affected family

Recommendation of Genetic Investigations after Genetic Counseling:

The judicial use of only relevant genetic tests requires special genetic expertise who decides the tests after thorough clinical & familial genetic evaluation with inheritance pattern, if any. The experienced medical geneticist / genetic counselor plays a pivotal role here in explaining the nature of the genetic disorder, relevant step-wise diagnostic tests, available treatment/ management& scope of prevention[11]. The cost-effectiveness while advising the expensive genetic tests is also looked after during GC.

The explanation of chromosomal reports in the case of Down syndrome with Trisomy 21 differs from that in balanced translocation of Trisomy 21 as the recurrence risk differs in both scenarios. Similarly, explaining the future risk in autosomal recessive conditions (viz.majority of IEMs) as 25% & in autosomal dominant conditions (viz. Tuberous sclerosis) as 50% is very important and is the job of experienced geneticists to arrive at the proper conclusion and convince the parents for mode of familial inheritance. The baseline risk & empirical risk based on the observed data in the population for Mendelian, Non-Mendelian, or chromosomal disorders causing the motor or mental deficits are often used to convince the parents.

Additionally, genetic counseling takes care of confidentiality, privacy, beneficence, justice, informed consent& ethical issues arising out of carrier screening, diagnostic & prenatal genomic testing[12,13].In India, we follow ICMR Ethics guidelines[14]. The communication skills of the genetic counselor play a significant role here unlike the clinician, who probably cannot devote much time from their busy routines. The genetic counselors are trained to -1) educate parents,2) genetic testing procedures,3) develop communication skills, 4) how to provide socio-psychological support& 5) consideration of ethical, social & legal issues associated with genetic counseling[15,16].

No doubt the changing digital world such as smartphones, artificial intelligence, automation

& digital communication will certainly play a significant role in GC practice in India, especially in communicating with the rural & tribal population.

Role of A Genetic Counselor: The genetic counselor is always a team member of patient care by providing genetic communication services. Genetic counselors and genetic counseling also form a strong bridge between physicians and patients while providing all genetic-related information to both the patient and the consulting physician.

Since 1970, the special genetic training in clinical, laboratory & counseling aspects of GC to medical & non-medical graduates & postgraduates emerged, creating the 'Genetic Counselor' as a separate profession. The counselor is trained in medical genetics, diagnostics & clinical aspects of genetic conditions, documentation of family & pedigree information, recognition of inheritance patterns & risk estimation, communication & empathy towards affected family, information on available options & further measures, and finally support in decision-making/ decisions made [10]. Several countries started appointing trained genetic counselors in hospitals & clinics realizing the acute need for genetic counselors.

India has witnessed the entry of genetic counselors as a separate entity only in this decade and mostly it is confined to developmental &behavioral pediatrics and reproductive genetics. Because, the last few decades have witnessed a transitional period of public health efforts shifting from infectious to rare & common genetic disorders through rare disease policy, treatment funds for the management of affected patients, prevention of birth defects in children programs, etc.

Thus, the genetic counselor advises the patients on appropriate genetic investigations based on the available genetic technology & approved methods. Secondly, to prevent the happening of a genetic disorder/ birth defect again in that family by explaining the ways & means of preventing the specific genetic disorder by pretest & post-test GC during prenatal diagnosis. It is thus very important that a genetic counselor dealing with developmental disorders must have updated genetic knowledge& experience to accurately & reliably implement it for the patient's benefit[17].

The care, sympathy, understanding & insight into the emotional aspects of the parents of a developmentally delayed child are given the highest priority. The ability to judge whether parents understood a scientific explanation & their reactions is a significant part of this GC communication.The counselor also has the knowledge about the ancillary needs of the patients. The burden of the disease may vary from clinical \ social \ and financial toemotional factors and differs from individual to individual. Hence, the GC is always aimed to promote informed choices & adaptation to cope with a genetic condition.

Dilemmas during Genetic Counseling:At times genetic counselors may face some real dilemmas when problems like previous abortions, abnormal births, and occasional false paternity are learned. The principal obstacles to effective genetic counseling are emotional conflicts and a lack of knowledge of genetics and biology. Occasionally, disputes arise about the significance of laboratory findings, especially about the possibility of maternal cell contamination in a prenatal sample or genuine doubt of chromosomal abnormality present in the parents or revealing the findings and interpretations between professionals and parents. All these need to be tackled by the counselor with the highest efficiency & confidence. Because the parents of a developmentally delayed child are

soon going to approach in future pregnancy for prenatal genetic counselingfor the next healthy baby or relatives at risk may contact for GC [18].

The genetic counselor, hence follows systematic protocol from starting the session till ending the session. The experienced and mature genetic counselor tackles every issue with remarkable calmness & patience. It must be remembered here that the counselor's role is to support, promote& help in taking decisions by keeping professional standards of respecting goals, beliefs& cultural values[19,10].

Impact of Genomic & Digital Technology in GC Practice in India-

In the era of genomic technology, the interpretation of Microarray or Next Generation Sequencing (NGS) reporting, managing incidental findings to patients is still a complex phenomenon; not yet fully understood and universalized with consensus. The guidelines of the American of College of Medical Genetics are followed for developmental disorders as well but it may not always hold true for our genetically varied & ethnically different population. This complex genomic understanding is not expected by the referring pediatricians or neonatologists who must in coordination with a genetic counselor decide the necessary genetic investigations & further genetic counseling to answer all the queries of the patient[20].

Advances in genetic science and biotechnology have also led to the discovery of new genes for many developmental disorders and updating knowledge about it is very important.As a result, the knowledge base for genetic counseling has become important in assisting patients with accessing timely screening, adopting healthy behaviours, and making decisions about obtaining genetic testing. The new genetic technologies help in the diagnosis & further confirmation of a raredisorder. It then becomes practical to calculate the recurrence risk in the affected family[21]. Internationally, genetic testing is shifting toward gene panels and genomic testing, including cytogenetic microarray, whole exome, and whole genome sequencing to improve diagnostic yield and cost-effectiveness using different algorithms[22,23]. The parental genetic testing in a developmental disorder is essential to predict the *de novo*or inherited mutation while calculating the future recurrence risk in the parents using these advanced technologies.

Digital tools have been part of medical genetics practice for decades, such as internet or CD-ROM-based tools like Online Mendelian Inheritance in Man and Pictures of Standard Syndromes and Undiagnosed Malformations in the 1980s.Technology can help in at-risk patient identification, assist in generating a differential diagnosis, improve efficiency in medical history collection or pedigree charting and risk assessment, provide educational support for patients, and streamline follow-up.Thus, genomics & enormous data generated coupled with bioinformatics & digital technology can play a vital role for GC in developmental disorders in India,considering about 27 million births per year.

Working as a medical geneticist& counselor for more than 3 decades, the author remembers the efforts to convince initially a karyotype test in Down syndrome child -the most common chromosomal abnormality causing mental deficiency- to pediatricians& their reluctance about advising genetic tests since there is no treatment for cure. Albeit the scenario has now changed. But there is still much to be done and genetic counseling professionals can greatly contribute to awareness & education of genetic

science not only among pediatric professionals but also to the public at largeconsidering the community genetic approach[6].

Conclusion- Geneticcounselingin developmental disorders is both an art andscience involving not only the use of technical genetic knowledge and precisemedical diagnosis but also the accurate dissemination of genetic information in atactful, empathetic manner with the help of accurate tests.In case of a developmental disorder with or without behaviour problems, GC is done keeping in mind, the objectives&principles to be used, the process & steps involved, various types of counselees encountered, the knowledge about the genetic condition, genetic evaluation using different diagnostic tests, recurrence of risk estimate, prevention modalities as well as the psycho-emotional and ethical issues. In the end, it is ensured that parents /patients/family are thoroughly satisfied and must be able to take a decision instead of placing them in a state of dilemma. In India, it is a budding specialtyto do GC for developmentally delayed children and their families.

Acknowledgment: The author is grateful & expresses her sincere thanks to all the referring doctors and patients throughout the decades of practice as medical geneticists and genetic counselors.

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Indian Journal of Developmental & Behavioral Pediatrics
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RESEARCH ARTICLE

Impact of maternal and neonatal parameters on the type of anxiety among parents of neonates admitted in Neonatal Intensive Care Unit

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Author contribution:1,2,3& 4 were involved in the conduct of the study from conception, design, drafting the document.

Abstract:

Background: Various factors operating in the child, mother and the environment in the NICU cause considerable anxiety in the mothers leading to further stress and other parenting issues. Hence it is important to understand the level and type of anxiety in these mothers which would affect the mother. Thus, it becomes important to understand the levels of anxiety experienced by the parents and its association between various sociodemographic factors in mother and infant characteristics. **Methodology:** This cross-sectional study was conceived to assess the anxiety levels and 100 mothers were recruited after getting appropriate approvals and consent from them. Data was collected using a preset questionnaire and State and Trait Anxiety inventory scale. **Results**: When both parents were interviewed, 91% of mothers and 43% of fathers were found to be anxious. A significant difference was found in the values of 2 types of anxiety (State anxiety and Trait anxiety levels). Though State anxiety levels were significantly different between mothers and fathers of NICU babies with mothers experiencing more anxiety levels when compared with fathers, trait levels were the same. Except for supporting family members, none of the factors like age, educational status, occupation, or income level had any significance between the state or trait anxiety levels. When mothers were allowed to handle babies gently, there was a significant reduction in State anxiety levels,while Trait anxiety levels remained unchanged. None of the other baby factors including low birth weight had a significant effect on anxiety in the long run. **Conclusion:** This study brings out the importance of addressing anxiety in mothers with NICU babies; to assess the type of anxiety separately and deal with the factors thatincrease it separately. It also brings out the fact that the general nature of the parent which brings out the trait was not influenced considerably by NICU admissions.

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Introduction:

Many common problems during the newborn period like prematurity, maternal health issues, difficulties during labor and birth, respiratory distress syndrome, and hemolytic anemia of newborns may require NICU admission. This can be traumatic and stressful to the parents, mainly the mother which in turn leads to affecting the mother-baby relationship and development of the baby. Stress is further aggravated when they find to their shock that the mother/father wouldn't be able to take care of the baby themselves, and the presence or absence of economic support or social supportadds to it. Mothers of neonates admitted to the NICU exhibit high levels of anxiety during the period of hospitalization. Early identification of anxiety levels has implications for the support of mothers during the hospitalization of their newborns. NICU mothers experience multiple stressors related to preterm birth, the medical condition of the infant, the complexity of the NICU environment, and the perceived vulnerability of the infant [1]. These can put mothers at risk of experiencing psychological distress, such as anxiety. In addition, parents of NICU infants may be predisposed to poor emotional functioning, anxiety, and mood disorders [2].It is important for mothers of NICU babies to seek support from family, friends, and healthcare professionals. Family support is negatively correlated with maternal state anxiety and maternal trait anxiety [3]. In addition, there are several support groups and resources available.

This study was conducted on parents of neonates admitted to NICU, with the following objectives:

1. To determine the levels of anxiety experienced by parents of babies admitted to NICU
2. To find out the association between anxiety level and sociodemographic and clinical variables of mothers and their newborns.

Materials and methods:

Study design:

This was a cross-sectional study done in Saveetha Medical College, Thandalam, a sub-urban area of Chennai, TN, India over 12 months from September 2022 to August 2023. Parents of Neonates admitted tothe NICU were the study population. All parents whose neonates were admitted tothe NICU for more than 24 hours and gave their valid consent for participation were included in the study. Those parents who did not wish to take part in the study or did not give consent after expressing willingness were excluded. All the participants were explained about the study, in their mother tongue and a valid consentwas taken. All willing parents were selected by convenient sampling and the questionnaire was administered by face-to-face interview method.The sample size was set to be 100. Power analyses were used to determine the sample size; A power analysis based on a previous study by Yurdakul et al., got a sample size of 95 with 85% power [13]. Hence, 86% power was attained with the first 100 mothers who agreed to participate in the study.

Data was collected using a pre-determined Proforma and Spielberg's State and Trait Anxiety Inventory scalewhich consists of questions regarding anxiety.This Likert-type scale psychological inventory developed by Spielberger et al measures two types of anxiety: the temporary condition of "state anxiety", or anxiety about an event, and the more general and long-standing quality of "trait anxiety", or anxiety level as a personal characteristic. It has 40 items: 20 items for state anxiety (S anxiety)

and 20 items for trait anxiety (T anxiety). Scores range from 20 to 80, the higher the scores greater the anxiety. Total scores obtained from each scale were evaluated separately. To this value a predetermined and unchanged number was added; for state anxiety, it was 50and for trait anxiety, it was 35. The subsequent result was the individual's anxiety score.

The descriptive questionnaire form was created which contained the socio-demographic details of mothers, certain details of the newborns, opinions of mothers regarding the NICU, and the status of their baby in the NICU. It also had a rough grading of perceived anxiety of the parents as mild, moderate, or severe.

Data was collected ensuring strict privacy and confidentialitywere maintained throughout the study. Performa had sociodemographic details of the parents and a rough classification of perceived anxiety as mild, moderate, or severe by the parent.

Statistical analysis:The collected data were numerically coded and entered in Microsoft Excel 2010, and then analyzed using SPSS-Version 23.0., (SPSS Inc, Chicago, USA). Data was analyzed by calculating Percentages and Proportions. Statistical test like Odds ratio and Chi-Square was used to assess the factors associated with the study variables. Descriptive statistics (mean, SD), Student's t-test (in two-group comparisons in which parameters exhibited normal distribution), and the Mann-Whitney U test (for 2-group comparisons in which parameters are not in normal distribution) were used. Values where $p<0.05$ were considered as significant.

Results:

Most of the parents reported tension and anxiety in the days their child was in the NICU. When asked about the level of tension they felt when their child was taken to NICU, eighty-nine percent of parents reported tensed;of which, 40 % reported 'Often', 24% said 'tensed the whole day', 28% said 'somewhat tensed' and 8% felt 'tensed only some times'. Almost 70% of the parents said they felt strained and were worrying about possible misfortune and more than 70% of parents said the stress and anxiety made them indecisive during their stay in NICU. Only a small percentage, i.e., 10 % of parents said they felt calm or at ease and self-confident during the NICU stay.

When both parents were interviewed, 91% of mothers and 43% of fathers experienced feelings of anxiety. The sex of babies did not have any impact on the number of parents who perceived anxiety. The number of anxious motherswas more in the primary or below group(n=19/100), followed by (n=44) 44%of them being degree and above.

However, when analyzing the anxiety among mothers alone using STAI, a significant difference was found in the values of variables between the 2 types of anxiety. The mean age of mothers in years was 25.69±4.28 SD. The socio-demographic parameters are as in Table 1.

Table 1: Demographicfactors:

Demographic characteristics	**Mothers with new-borns in a NICU**	
Age	25.69±4.28(Mean+/-SD) years	
	n	**%**
Educational status		
Primary school	19	19
High school	37	37
Degree and above	44	44
Occupational Status		
Working	29	29.0
not working	71	71.0
Income level		
low	24	24.0
Middle	56	56.0
High	20	20.0
Supporting family members		
Present	81	81.0
Not present	19	19.0

State anxiety levels were significantly different between mothers and fathers of NICU babies with mothers experiencing more anxiety levels when compared with fathers($p<0.001$). However, trait anxiety levels were not significantly different between both parents(Table:2).

Table 2: State –Trait Anxiety Levels of Mothers Vs Fathers

	Mothers with new-borns in a NICU	**Fathers with new-borns in a NICU**	**Statistical Analysis**
	Mean±SD	**Mean±SD**	**Values(t; p)**
State Anxiety Levels	49.20±5.65	43.41±6.61	t=4.718, $p<0.001^{*}$
Trait Anxiety Levels	41.02±5.29	39.68±5.99	t= 1.1877, p=0.238

Independent samples t-test; $^{*}p<0.05$

When the difference in the two types of anxiety were analyzed against maternal parameters, none of the factors like age, educational status, occupation,or income level had any significance between the state or trait anxiety levels. The only significant parameter was the presence of supporting family members(p=0.003) (Table 3)

Table3: "State-Trait Anxiety Levels" vs maternal Parameters.

Characteristics STAI -S		**Mothers with new-borns in a NICU**	
		STAI -T	
Age	r	0.103	-0.112
	p	0.314	0.277
		MEAN±SD	**MEAN±SD**
Educational Status			
Primary School		49.40±6.49	41.03±6.18
High School		46.37±7.24	39.03±5.52
Degree and above		51.28±5.49	40.52±7.24
		F=1.049,p= 0.365	F=0.761,p=0.487
Occupational Status			
Working		47.79±6.59	38.92±4.94
Nonworking		47.86±6.52	41.32±5.25
		t=0.264,p=0.815	t=1.455, p=0.164
Income levels			
Poor		46.64±7.81	41.37±2.92
Middle		47.09±6.73	39.62±5.82
High		46.43±4.03	41.67±4.54
		F=2.620,p=0.081	F=1.285,p=0.259
Presence of Supporting family members			
Yes		46.60±6.12	41.03±4.46
No		49.60±6.61	38.94±3.54
		t=3.027,p=0.003*	U=831.00,p=0.474
Previous NICU experience			
Yes		45.40±5.15	40.93±4.25
No		50.2±5.51	38.72±3.35
		t=3.135,p=0.002*	U=822.00,p=0.465

When the difference in the types of anxiety was assessed with selected infant characteristics like birth weight, sex of baby, and updating daily status there was no significant difference between the two. However, allowing for touch therapy or in the baby care activities quite early during NICU stay produced a significant effect in state levels than trait levels. (p=0.048) (Table 4)

Table 4: "State-Trait Anxiety Levels" according to infant Parameters.

Birth Weight			
	≤2500 gram (n=32)	**>2500 gram (n=68)**	**Significance**
	Mean ± SD	**Mean ± SD**	
STAI -S	47.95±5.70	47.31±7.36	U=1084.00, p=0.729
STAI -T	40.13±4.78	38.31±5.85	U=1004.00, p=0.350
Gender of the Baby			
	Female (Mean ± SD)	**Male (Mean ± SD)**	
STAI S	48.12±7.13	47.98±6.32	U=1062.50, p=0.349
STAI-T	39.72±6.45	41.02±4.71	t= -.956, p=0.350

Effect of daily counselling on babies status				
	Yes	**Partially**	**No**	
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	
STAI -S	47.64±6.64	48.44±7.00	52.37±5.37	KW=6.367, p=0.041*
STAI-T	39.55±3.41	40.21±6.01	40.81±5.39	KW=.246, p=0.884
Involving in early interaction with baby like allowing to touch, change diaper				
	Yes	**Partially**	**No**	
	Mean ±SD	**Mean ± SD**	**Mean ± SD**	
STAI-S	45.47±6.42	46.44±6.14	50.35±7.79	F=3.136, p=0.048*
STAI -T	40.42±5.53	40.50±5.77	39.09±5.13	F=.500, p=0.608

*p<0.05

Discussion:

This study was conducted in a tertiary care center where recommended protocols for parent care, counseling, and NICU care were in place; hence, the analysis should be seen contextually. When both parents were interviewed about feelings of anxiety, 91% were mothers and 43% were fathers reported feeling anxious. The same trend was found in many other studies also, where more number of mothers were experiencing anxiety and stress. The sex of babies did not have any impact on the number of parents who perceived anxiety. The number of anxious motherswas more in the primary education or below group(n=19), followed by 44% in the degree and above educational status group. Similar reporting of experiencing stress was also noted by others.[4],[6] Reporting of anxiety was the same in parents of both male and female babies which is in contrast to the study byGurpreet Singh [5]and similar to the study by Miles Ms and Masubrema,[4] [7]The anxiety seems to be higher in mothers than the fathers with 91% of mothersdeveloping anxiety compared with only 43 % of fathers who had anxiety. This wassimilar to many studies [5],[6,][7][8][9][10]and was in contrast to studies by Miles MS et al.[4]

The anxiety levels in lesser educated people werehigher than in higher educated people, 88%(n=16/19) in lesser educated parents as

compared to 70%(n=29/37) in higher educated parents which is similar to Ganguly and Carter JD[4,6]and in contrast to Gurpreet.[5, 10]However, this trend is found to reverse in those who are degree and above, where we have the maximum level of mean anxiety level. This could partly be due to increased knowledge levels about conditions and more medical/Internet exposure this population might have gotten. The higher anxiety levels of parents with previous NICU admission don't show any significant alteration from the parents with no previous NICU admission of their children, which is in contrast toa study by Binu et al[3]This means that state anxiety remains the same despite previous NICU exposure. This points to the need for mandatory counseling for the parents, especially the mothers, irrespective of the previous NICU exposure, each time counseling from the caregivers is needed.

The anxiety levels in parents with previous neonatal deaths were seen to be increased with 86 % of parents with previous exposure to neonatal deaths in contrast to 77% of parents with no neonatal deaths. This study was also in contrast toa study by Gurpreet [5] which showed that previous NICU experience, irrespective of the outcome (recovery/death of the neonate), and was found to be associated with significantly lower anxiety levels, which showed higher stress in mothers who have no previous NICU admission.[9],[12]

The State anxiety levels were significantly different between mothers and fathers in the present study. However, the Trait anxiety level remains insignificant between the parents. This is a significant finding of the present study which points to the fact that state anxiety manifesting like fear, nervousness, discomfort, etc is higher in mothers than fathers of NICU babies. This is the temporary anxiety referred to as how a person is feeling at the time of a perceived threat. The trait stress levels-the feelings of stress, worry, discomfort, etc that one experiences on a day-to-day basis, are the same in both parents. This indicates that the sex of parents does not affect usually how people feel across typical situations that everyone experiences daily in the context of NICU admissions.

When the difference in stress and Trait type anxiety were analyzed against maternal parameters, none of the factors like age, educational status, occupation, or income level had any significance between the state or trait anxiety levels. Only the presence of supporting family members was found to be significant($p=0.003$). This indicatesthe need for effective support systems to alleviate the anxiety of mothers in difficult situations in the NICU and the need for anticipatory advice to them. However, in the present study, allowing the mother tohandle the baby early allows a reduction of state-level anxiety and does not affecttrait-level anxiety. A recent study noted that maternal or infant characteristics do not correlate with maternal anxiety. However, they found that the stress experienced by mothers had a significant correlation with anxiety and was found to be associated with state and trait anxiety levels. [14] Another study also identified that state anxiety levels among mothers of NICU babies were higher than those not in NICU. [15]It is reported that such mothers have higher levels of depression and anxiety levels than those with healthy-termbabies. [16]

This study gives insight into the modifiable factors among child and mother parameters that can directly affect the quality of life and mental health of parents in the immediate postpartum period. Further research into the effect of the different types of postpartum anxiety on childcare, needs to be evaluated based on the parenting behavior. This may give further insight

into how such anxiety may affect parenting and its effect on child development.

Conclusion:

This study has shown that almost all parents who have their children admitted to the NICU have anxiety regarding their child's health. Among the maternal parameters, the only significant parameter was the presence of supporting family members and no other factor including age, educational status, occupation, or income level had any significance between the state or trait anxiety levels. Even in the context of previous exposure of parents to NICU care, since parents across socioeconomic and educational backgrounds feel anxious, early exposure to newborn care and effective counseling to impart knowledge of the babies' condition should be given.

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RESEARCH ARTICLE

Prevalence and correlates of scholastic problems among undergraduate nursing students in a tertiary level Nursing college in Trivandrum, Kerala

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Abstract

Introduction*: The academic competency of nursing students is a phenomenon of growing interest because of its economic impact and its negative effects on the availability of future nurses in different healthcare systems. The present study is a cross-sectional study investigating the prevalence of scholastic problems among nursing students, its socio-demographic correlates, and the effectiveness of an intervention tool in improving the perceived scholastic problems and study habits.* ***Methods****: The prevalence of the perceived scholastic issues and pre-post data was ascertained through a self-administered Teenage Screening Questionnaire collected electronically. The intervention was delivered by a didactic discussion over video conferencing.* ***Results****: 42.1% of students had scholastic problems and 57.5% had study habit problems. There was a statistically significant improvement in both domains after intervention.* ***Conclusion****: The findings show the high prevalence of scholastic issues among undergraduate students in nursing colleges and support the need for institutional-level initiatives to address scholastic issues and the resultant stress.*

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Key words: *Nursing students, scholastic problems, study habits, scholastic interventions*

Introduction

Nearly 10-30% of young adults between 15 – 24 years suffer from health-impacting behaviours and conditions that need the urgent attention of policymakers and public health professionals[1]. As in India, academic achievement is often the basis for a vocation and productive adult life; an integrated coordinated approach for providing academic support for young adults is required. The

success of any educational system is measured by its academic performance or how well students meet the standards set out. Currently, nursing students' academic failure is a phenomenon of growing interest because of its economic impact and its negative effects on the availability of future nurses in different healthcare systems.

Nursing education provides large human resources in the health sector and to become a professional nurse, the students have to undergo a challenging learning process, entirely different from the school education system. Deary et al. reported burnout and stress as a major contributor to student dropout or failure[2]. As reported by student exit interviews, family difficulties, academic failure and financial issues are the main reasons for leaving nursing school[3,4]. Nursing college students on admission to the college, also have to cope with significant changes in lives like; (i) balancing studies and social life, (ii) facing a teaching pattern different from school, (iii) getting prepared for a future career, (iii) moving away from home, and (iv) taking responsibility for themselves, all of which can be stressors affecting their academic performance and mental health[5].

In a study involving 1892 adolescents of 13 to 19 years age group belonging to different categories of schools assessed using TeenageScreeningQuestionnaire--Trivandrum and Study Habit Rating Scale, it was observed that the factors affecting scholastic performance were; daily study pattern, family environment, education status of parents, personal distractions, and attitude towards studies. On multivariate analysis the predictor variables for poor scholastic performance were; (i) lower studying daily lessons, (ii) poor concentration in studies, (iii) lower education status of father, and (iv) unhappy family, showing that it is feasible to identify determinants of scholastic performance and plan intervention strategies at school level[6]. In a study conducted among nursing students in Kerala found that 59.7% of students have total marks between 50% to 60% while 24.7% of students have marks within the range 60%-75%, 14.9% of students have below 50% in scholastic performance whereas 0.60% student has a total percentage of marks above 75%. The study also revealed that the study habits and scholastic performance share a very strong relationship ($p<0.05$)[7]

This study was done to understand the scholastic problems faced by young nursing students and to determine if a structured intervention can impact the degree of perceived scholastic problems.

Objectives

1. To estimate the prevalence of scholastic issues among female nursing students.
2. To assess the study habits and other contributing factors affecting scholastic performance among female nursing students.
3. To develop and deliver a structured teaching programme for improving the study habits of female nursing students.
4. To assess the effectiveness of intervention by comparing pre-postscores of scholastic issues and study habits

Methodology

This cross-sectional study was conducted in the NIMS College of Nursing in collaboration with adolescent health services of NIMS Spectrum Child Development Research Centre (CDRC), over a period of 6 months. Female undergraduate nursing students from the first to fourth year, who consented to participate in the study, were included. The census method was adopted for recruiting students using the college admission

register. The study tool used for the purpose was the Young Adult Screening Questionnaire, appropriately modified from the Teenage Screening Questionnaire, combined with a personal data sheet recording the socio-economic details of the participants.

After getting clearance from the Institutional Ethical Committee and college authority (Reg No ECR/218/Inst/Ker/2013/RR-16 Approval no NIMS/IEC/2021/04/10), informed consent was obtained from individual students. Pre and post-data were collected online, in view of the covid 19 epidemic. The link of the questionnaire converted into Google form was sent to the students via WhatsApp groups for each class. The responses provided were automatically uploaded and saved in Google Drive. The test results were thereafter analyzed using descriptive statistics and pre and post-test results were compared using Wilcoxon signed rank test.

Intervention package: The broad contents of the intervention package included awareness and identification of problems like attention deficit, exam anxiety, and procrastination along with information on good study habits. This intervention was given online via a pre-arranged one-hour didactic session on Google Meet, where the students were provided access to the module along with ample time to clear their doubts. Those who needed additional counseling services were attended by Consultants in Adolescent Medicine and Clinical Psychology at the NIMS-Spectrum-Child Development Research Centre.

The module was prepared drawing from the experience of conducting the Students Guidance and Support Program of Kerala University of Health Sciences. The same had been adequately piloted on a sample of B.Pharm and Dental students and was found to be simple and feasible. The module included preventive and proactive instructions directed towards every student and comprised of basic information on good study habits, strategies to counter procrastination, distraction, exam anxiety, and personal stressors as well as general information on neurodevelopmental disorders like ADHD, SLD, and psychiatric disorders like anxiety, depression and OCD.

Results

The study included 221 female nursing students from the NIMS College of Nursing. Socio-demographic characteristics of study participants were;

- *Age*: ≤20 years: 102 (46.2%), >20 years: 119 (53.8%);
- *Religion*: Hindu: 109(49.3%), Christian: 92(41.6%), Muslim: 20(9%);
- *Type of family*: Nuclear: 181(81.9%), Extended: 25(11.3%), Joint: 15(6.8%)
- *Residence of family*: Urban: 160(72.4%), Rural: 61(27.6%)
- *Current residence of students*: Home: 98(44.3%), Hostel: 123(55.7%)
- *Socio-economic status*: APL: 124(56.1%), BPL: 97(43.9%)
- *Academic year*: 1st year: 56(25.3%), 2nd year: 56(25.3%), 3rd year: 59(26.7%), 4th year: 50(22.6%)
- *Nursing as the preferred choice of course at the time of admission:* 77.8%.
- *Regretted selecting nursing as their choice of course:* 70.6%.
- Secured marks above 60% in their final examinations: 85.5 %

Prevalence of scholastic problems and poor study habits

Table 1: Scores in scholastic issues and study habits

Scholastic issues	***Never*** *N (%)*	***Sometimes*** *N (%)*	***Always*** *N (%)*
Difficulty concentrating in class	62 (28.1)	157 (71.0)	2 (0.9)
Difficulty in following daily lessons	61(27.6)	149(67.4)	11(5.0)
Anxiety/fear related to exams	25(11.3)	118(53.4)	**78 (35.3)**
Do not study/ read daily lessons	30(13.6)	178(80.5)	13(5.9)
Difficulty in understanding/studying any subject	55(24.9)	158(71.5)	8(3.6)
Personal Problems which disturb studies	143(64.7)	75(33.9)	3 (1.4)
Love affair which disturbs studies	146(66.1)	72(32.6)	3(1.4)
Problems that disturb studies at home	136(61.5)	80(36.2)	5(2.3)
Problems which disturb studies at college	211(95.5)	9(4.1)	1(0.5)
Broken homes which disturb studies	136(61.5)	80(36.2)	5(2.3)
Study habits			
Have a daily study schedule	57(25.8)	137(62.0)	7(3.1)
Ensure a quiet environment free from interruptions and distractions for study	28(12.7)	87(39.4)	**106 (48.0)**
Arrange all necessary study materials in the study place	9(4.1)	83(37.6)	**129 (58.4)**
Use study place for other activities like sleeping, eating and gaming	13(5.9)	98(44.3)	**110 (49.8)**
Have a study place comfortable with proper light, ventilation, and seating	6(2.7)	51(23.1)	**164 (74.2)**
Show outward interest during lectures like attentive expression and posture to self-motivate internal interest	37(16.7)	158(71.5)	26(11.8)
Resist distraction by sitting in front of the classroom, away from disruptive classmates, and by focusing on the instructor through listening and note-taking	67(30.3)	131(59.3)	23(10.4)
Take a break in between study time	10(4.5)	109(49.3)	**102 (46.2)**

Study subjects were categorized as with or without scholastic problems and poor study habits, taking individual medians as the cut-off score. Based on the cut-off,42.1% of students had scholastic problems and 57.5% had study habit problems.(Table 1)

Table 2: Sociodemographic associations of scholastic problems

Sociodemographic variable	Scholastic problems		Chi sq	P value
	Present	Absent		
Year of study				
1st year (56)	23 (41%)	33(59%)		
2nd year (56)	29 (51.7)	27 (48.3)	14.839	**0.002**
3rd year (59)	31 (52%)	28 (48%)		
4th year (50)	10 (20)	40 (80)		
Age				
≤ 20 years(102)	50(49)	52(51)	3.741	**0.05**
>20 years(119)	43(36)	76(64)		
Arrears in university examination				
Absent (176)	66(37.5)	110(62.5)	7.157	**0.006**
Present(45)	27(58.6)	18(41.4)		
Place of residence				
Rural(160)	74 (46)	86 (54)	4.133	**0.04**
Urban(61)	19 (31)	42(69)		

Assessment of the correlates yielded the following results;

- The fourth-year students had the least scholastic problems (10.8%) (p=0.002) (table 2)
- A statistically significant relationship between scholastic problems and lower age (<20 years, p=0.05), absence of arrears in university examination (p=0.006), and place of residence (p=0.04) was observed. (Table 2)
- No statistically significant relationship was found between scholastic problems and study habits, choice of course, percentage of marks, or socio-economic strata.

Table 3:Pre and post-intervention results

	Scholastic problems		Study habits	
	Pre	Post	Pre	Post
Mean	6.10	5.68	10.79	11.26
Median	6.0	5.0	11.0	12.0
Standard Deviation	2.95	3.08	2.45	2.52
Range	14	13	13	12
Inter-Quartile Range	4	5	3	4
p value	0.005		0.03	

Wilcoxon signed-rank test demonstrated a significant reduction in pre-post scores of scholastic problems (p=0.005) and improvement in study habits (p=0.03), demonstrating the effectiveness of the intervention package.

Discussion

Academic achievement can be defined as the knowledge attained or skill developed in the subjects, usually assessed by test scores, by marks assigned by teachers, or by both. Literature reports that difficulty in coping with the academic workload can be attributed to poor study habits[8], procrastination[9], younger age[10], and personal stressors like financial problems[11,] which can be correlated with mental health. The choice of the course has also been found to have a significant correlation with perceived academic stress[12,13]. In our study, nearly half of the nursing students (42.1%) had scholastic problems and among them, the most common was 'always having anxiety/fear related to examination' (35.3%). We found a statistically significant relationship between perceived scholastic problems and younger age, place of residence, and arrears in University examinations, however, there was no correlation of perceived academic stress with study habits, percentage of marks, choice of course, or socio-economic strata. Our study also found lower levels of perceived scholastic problems amongst the final-year students, with the second and third-year students having the highest levels, which is similar to the findings of Ribeiro et al[14], who attributed the difference to a higher practical and clinical workload in these semesters. Even though poor study habits did not positively correlate with perceived scholastic problems in the nursing undergraduates, it is worth mentioning that 57.5% of the students reported study habit problems in our study;30.3% did not take class notes properly, 25.8% did not have a daily study schedule, 16.7% were not being attentive in class and 12.7% did not ensure an interruption-free study environment.

The main aim of our intervention package was to equip the students with ideas of self-motivation, self-regulation, and internal control, based on the principles of the attribution theory[15,16]. Even though it would have been desirable to conduct the intervention session on a face-to-face basis, in view of the COVID-19 pandemic, it was conducted online. Despite this limitation, students showed a statistically significant reduction in levels of perceived scholastic problems and improvement in study habits after the intervention. Our findings are similar to Tobar et al. study on medical students[17] which explores the efficacy of an online "study habits and motivation-based" interventional module. This suggests that a systematic intervention program can make a change in the lives of students with borderline performance. We believe that this model can be replicated in other nursing colleges too.

Conclusion

The findings support the need for institutional-level initiatives for nursing students to address scholastic issues and the resultant stress. Ongoing interventions and support systems may be relevant with multifaceted learning strategies and regular follow-up/feedback from mentors and/or counselors for nursing students.

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Autism – Beyond the child– Taking care of the parent's Quality of life

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Children diagnosed with autism spectrum disorder (ASD) have impaired social functions, exhibit repetitive, stereotyped, and self-stimulatory behaviour, and often exhibit a significant delay in the development of verbal interactions.[1]

The diagnosis of ASD can leave parents feeling shocked, confused and overwhelmed. Parents may experience a wide range of emotions, including denial, anger, guilt and sadness. They may feel like they have failed their child, or they may blame themselves for their child's condition. Parents may also worry about their child's future, wondering if their child will ever be able to live a normal life.

Stress experienced by parents of ASD children during parenting are significantly more and challenging than those with neurotypical children, especially in resource constraint settings like in India. It is estimated that many parents of children with ASD have to face additional issues such as stigma and psychological problems of stress and depression due to their child's behaviour, including poor quality of life.

In 1993 the World Health Organisation defined Quality of Life (QoL) as an individual's "perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".[2] QoL is a multidimensional concept which includes health and non-health-related functional domains. Various models of QoL are available, a widely accepted model for assessing QoL in the context of disabilities has been put forward by Schalock et al. This model proposes eight core QoL domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional wellbeing, physical wellbeing, and material wellbeing.[3]

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In a qualitative study by Saleh et al, looking at views of parents of ASD children, their responses fell into four out of eight of Schalock's domains; self-determination, emotional well-being, physical well-being, and material well-being. The major concerns were those pertaining to their children's future. Many wanted their child to achieve typical milestones, such as living on their own. With regard to emotional well-being, the discussion centered around personal fulfilment. Within this subtheme, parents equated QoL with being happy and with the absence of stress and problems. Pertaining to physical well-being, they

mentioned the lack of it, complaining that they were more often physically exhausted. [4]

Also, a study by Selvakumar N et al indicated the presence of depressive, anxiety, and stress symptoms among the mothers of children with ASD which can also lead to poor QOL.[5,6]

Correspondingly, given that it is recognized that parents and families are essential to the well-being of children with ASD, researchers, policymakers, and service providers need to recognize the importance of supporting them and allowing for their involvement in the intervention for their children. Parental support groups helps considerably in boosting a parent's sense of control over his/her well-being and for acquiring parenting techniques in these subgroup to prevent further issues impairing their physical and mental health. Further, the overall health can be improved to a great extent by measures like providing more support like home services for parents. Finally, healthcare professionals should discuss with parents the financial burden, options for financial resources and address the unmet needs of lower socio-economic families, as well as referring them to the relevant authority for availing appropriate assistance.

Therapies available for parents are:[7]

1) Cognitive Behavioural therapy: Problem solving education (PSE), Problem Solving Skills Training (PSST): There is statistically significant reduction of parental stress. [8]
2) Mindfulness therapy: Acceptance and Commitment Therapy (ACT): Parents showed reduction in mindful attention awareness scores, a trend towards lowering of stress.[9]
3) Parent training (PT): Parent Family Intervention (PFI)
4) Areas focussing on Post-traumatic Growth: Solution-focused Brief Therapy (SFBT): through psychoeducation with emphasis on positive psychological changes (such as development of spirituality, patience, compassion and strength).[10]

Recommendations: Despite the challenges that come with an autism diagnosis, there are ways for parents to cope and manage the stress that comes with it. Here are some suggestions:

1) Educate yourself about autism: Learning more about autism can help parents understand their child's condition and how it affects their behaviour, communication, and development. Understanding autism can also help parents advocate for their child's needs and communicate more effectively with teachers, therapists, and other professionals.
2) Seek out support: Parents of children with autism can benefit from connecting with other parents who have similar experiences. Support groups, online communities, and parent networks can provide a space for parents to share their experiences, ask questions, and receive emotional support.
3) Take care of yourself: Caring for a child with autism can be stressful and exhausting, so it's essential for parents to take care of themselves. This can include getting enough sleep, eating a healthy diet, and engaging in activities that promote relaxation and stress relief, such as exercise, meditation, or hobbies.
4) Advocate for your child: As a parent, it's crucial to advocate for your child's needs and rights. This may involve communicating with educators, healthcare professionals, and government agencies to ensure that your child has access to appropriate support, services, and accommodations.
5) Celebrate your child's achievements: Finally, it's essential for parents to celebrate their

child's achievements, no matter how small they may seem. Recognizing your child's progress and accomplishments can help you stay positive and motivated during challenging times.

An autism diagnosis can be a challenging and emotional time for parents. The diagnosis may leave parents feeling overwhelmed, isolated, and unsure about their child's future. However, there are ways for parents to cope with the stress and manage the challenges that come with raising a child with autism. By educating themselves, seeking out support, taking care of themselves, advocating for their child, and celebrating their child's achievements, parents can help their child reach their full potential and lead a fulfilling life.

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SUMF gene mutation presenting as hemimegalancephaly

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Abstract

Background: Multiple Sulfatase Deficiency (MSD) is an extremely uncommon inborn metabolic defect (IEM). The heterogeneity of the phenotypic spectrum is owing to the combined defects in the nine sulfatases currently associated with human illnesses. The extensive and multisystemic consequences of MSD principally include developmental delay and symptoms on the skeletal, neurological, cardiopulmonary, dermatological, and gastroenterological levels. **Clinical Description**: We describe clinical findings and mutation analysis of an 18-month-old male child with the complaint of recurrent seizure episodes and developmental regression. The whole exome sequencing revealed that the child was identified as a carrier for SUMF1(sulfatase modifying factor 1) gene deletion. **Management & Outcome**: On follow-up, the child is on polytherapy seizure medication and a registered case in REIC (Regional Early Interventional Centre), **Conclusion**: Recurrent seizures with developmental regression and hemimegalencephaly should prompt one to think of rare possibilities like a MSD. Though both hemimegalencephaly and MSD are rare, the association of it with MSD is frequent and is genetic.

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Keywords:

Hemimegelencephaly, multiple sulfatase, deficiency, developmental regression

Introduction

Multiple sulfatase deficiency (MSD) is a rare lysosomal storage disorder caused by the deficiency of all known sulfatases, which leads to the buildup of glycosaminoglycans and sulfated lipids. Sulfatase-modifying factor 1 (SUMF1), which is a gene that causes MSD, is located on chromosome 3p26[(1)] It exhibits the combined clinical phenotypes of several sulfatase deficits, which have characteristics of the following disorders: Metachromatic leukodystrophy, the X-linked disorders Hunter syndrome, Maroteaux-Lamy syndrome, the autosomal recessive conditions Morquio A syndrome, Sanfilippo A syndrome, Sanfilippo D syndrome, and the X-linked Hunter syndrome.

The most typical symptoms of the condition include psychomotor retardation, coarse face, hepatosplenomegaly, ichthyosis, and skeletal abnormalities such as scoliosis and dysostosis multiplex. Neonatal, moderate, and mild variants of MSD have been categorized based on the severity and age of onset[1,2].

According to the age of onset, there are three different forms of MSD: newborn, late infantile (0–2 years), and juvenile (2 to 4 years). The most severe type of MSD is neonatal, with a wide spectrum of symptoms similar to mucopolysaccharidosis and death within the first year. A rare condition known as hemimegalencephaly (HME) is characterized by the overgrowth of one cerebral hemisphere. It can appear alone or as a component of a syndrome like Klippel-Trenaunay syndrome, tuberous sclerosis complex, epidermal nevus syndrome, or hypo-melanosis of Ito(3,4) The triad of epilepsy, generalized developmental delay, and contralateral motor deficiency is traditionally linked to HME [4]. These patients' epilepsy is notoriously challenging to treat, and the majority of them suffer from poor neurodevelopment.A hemispherectomy is frequently carried out in children with HME and drug-resistant epilepsy (DRE) to lessen the burden of seizures[3]. Although these children may not become seizure-free, their seizure control and quality of life usually significantly improve.

Hemi-megelancephaly and multiple sulfatase deficiency are rare findings; but chances of both occurring in same child is frequent and is often not thought about. This will result in choosing a larger battery of investigations[4].

Here we present the case report of an 18-month old male child with complaint of recurrent episodes of seizure, developmental regression and neuroimaging suggestive of hemimegalencephaly.

Clinical Description:

We report the case of an 18mnth child born out of non-consanguineous marriage, with acute onset of abnormal body movements at 10mnths of age lasting for 10-20sec of all four limbs, at an interval of 2hrs for which he was taken to a clinic, where he was started on anti-seizure medications and the child had no residual neurological deficits post discharge.

After 3 months of seizure free period child again had an episode of seizures despite good compliance, for which the doses of anti-seizure medications were escalated. During this episode, he also developed developmental regression. After a month, he was re-admitted with similar complaints and anti-seizure medications were escalated again. On general examination, vitals were well within normal limits. No dry scaly lesions of skin suggesting ichthyosis, No organomegaly or abnormal urine odour. Fundus examination was normal. Neurological examination revealed head circumference to be 46.3cm. Motor, sensory examination was normal. Developmental assessment was done, DQ at 12-month age was 92% which regressed to 63% at 18-month age.

Investigations and outcome

All routine investigations were within the normal limits, X-ray spines, limbs showed no abnormality, ECHO was normal. Fundus and hearing assessment (done by BERA) was normal.MRI revealed Asymmetric left cerebral hemisphere slightly larger than right cerebral hemisphere with asymmetrically prominent left lateral ventricle may represent part of hemimegaloencephaly.Thickened gyri with blurring of grey white matter differentiationin left frontal lobe and along sylvian fissure , likely pachygyria polymicrogyria complex (Fig 2).Whole exome sequencing –revealed SUMF1

frameshift duplication on location exon 5 coding for Multiple Sulfatase Deficiency as likely pathogenic variant was identified.On subsequent visits epilepsy became poorly controlled despite polytherapy and so child was referred to higher center for epilepsy surgery.

Discussion:

MSD is a rare form of autosomal recessive inborn error of metabolism. One in a million births are affected by it. Less than 50 cases from around the world have been documented to yet. [1]

MSD is essentially a problem with sulfatase's posttranslational modification to its active form. The main catalytic residue in the active catalytic side of sulfatases is called FGly, and the formylglycine-generating enzyme converts cysteine into it (FGE).[2,6] In MSD, this enzyme has a malfunction. The SUMF1 gene, which codes for FGE, has been located, and mutations that lead to disease have been characterised.[6]

A rare cortical development disease called hemimegalencephaly (HME) causes one cerebral hemisphere to grow excessively. Patients experience severe seizures, hemiparesis, and intellectual retardation. Hemispherectomy is a common treatment for drug-resistant epilepsy[5,7].

The symptoms of the various sulfatase deficits are combined to form the clinical picture of MSD. Patients exhibit neurological degeneration and a metachromatic leukodystrophy-like neurodegenerative illness course. As seen in other mucopolysaccharidoses, organomegaly, dysmorphism, and developmental delay are also prevalent. Skin alterations and skeletal anomalies bring to mind X-linked ichthyosis type I, respectively. Additionally, to mental retardation, coarse facial features, seizures, leukodystrophy, tetraplegia, visceromegaly, ichthyosis, and dysostosis, patients with MSD may also experience these conditions. (1)With neurodegeneration causing early death within a few years after clinical beginning, early development may be normal after an often rapid clinical progression.

Clinical signs and symptoms in MSD patients vary greatly. There might not be the characteristic hepatosplenomegaly associated with MSD, and the neurological development might be delayed. Patients may experience minor mental retardation, macrocephaly, dysostosis multiplex, and corneal clouding, however ichthyosis is not present in the Saudi variety of the illness[6]. Yis et al.'s[8] reported two MSD patients from Turkey. They had hepatosplenomegaly, ichthyosis, coarse faces, spasticity, and mental impairment. They were discovered to be homozygous for the unique missense mutation c. 739G > C, which results in the substitution of the amino acid p.G247R in the SUMF1 in their patients.

SUMF1, which is found on chromosome 3p26, is the MSD-causing gene. [3] The SUMF1 gene has been described as carrying nonsense, missense, microdeletion, and splicing mutations. The implications of SUMF1 mutations on each sulfatase's activity vary, and there is no correlation between the type of molecular defect and the severity of the symptom.

A rare cortical abnormality known as hemimegalencephaly (HME) is characterised by the enlargement of one cerebral hemisphere. Although there have been suggestions of genetic connections and a correlation with mTOR (mammalian target of rapamycin) pathway alterations, the aetiology is not entirely understood. [7] Although other neurological signs include developmental delays, hemianopia, and motor weakness have been identified in recent literature, seizures are the most typical presentation of HME in patients. Anti-epileptic medications are rarely effective at controlling the seizures linked to HME (AEDs). A successful

way of treating multi-drug resistant seizures is hemispherectomy.

Conclusion:

HME with resistant seizures are good candidates for hemispherectomy due to the numerous immediate and long-term risks of polypharma. This is more so when associated with disorders like MSD with multisystem involvement. Hence this rare combination, if suspected, should be investigated early with a genetic analysis to enable informed decision making.

Lessons learnt

Though Hemimegelencephaly is a rare finding its occurrence with multisystem involvement and regression with recurrent seizures should prompt us to think of disorders like MSD with which the association is fairly frequent.

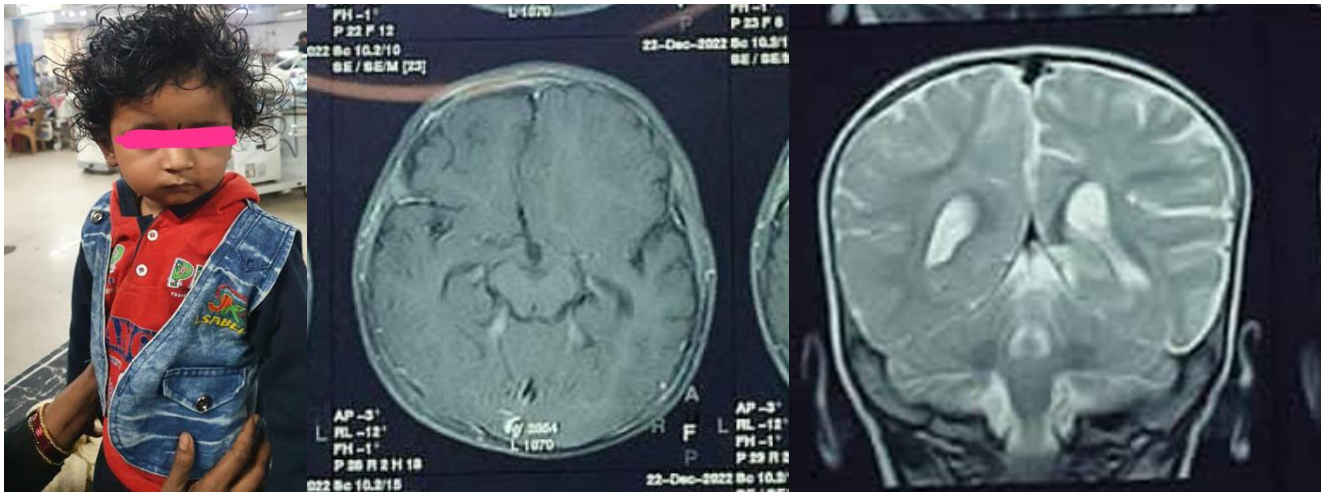

Figure 1 Clinical picture of child and MRI images

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   c. For Consensus Guidelines 3000 to 3500 words.
   d. For updates 500 to 1000 words.
   e. For Case Reports 500 to 1500 words.
   f. Commentary 1000 to 1500 words
   g. Letter to editor 500 words
5. Introduction – should state purpose of study & give brief review of pertinent literature. Cite only those references that are essential to justify the purpose of study.
6. Material & Methods should follow the introduction & should provide enough information to permit repetition of experimental work/ project, giving how the study was designed, carried out and data was analyzed. State whether study was approved by ethics committee or not. Describe statistical analysis methods used with required details. Give actual p-values, t-values define statistical terms, symbols and abbreviations.
7. Results should describe the outcome of study giving relevant data. Avoid repeating in the text all the data depicted in tables or illustrations: Tables (numbered in roman numerals) & illustrations (Numbered in Arabic Numerals) should be prepared on separate sheet(s) with headings or legends. Minimum size of illustrations should be 8 x 10 cm. Top of figure should be marked by an arrow on its back as well as figure's number and author's name on left side of photograph. Cite the tables/ figures in the text at appropriate places.
8. Discussion ordinarily should not be more than 1/3 of total length of manuscript. New and possible important findings of the study should be emphasized, as well as any conclusions that can be drawn. The Discussion should compare the present data to existing literature. The implications of the findings and their limitations, including potential for future research should be discussed. New hypotheses and clinical recommendations that are appropriate should be clearly identified.
9. References - In general, the number of references should not exceed 40 for original articles, 50 for review articles and 15 for case reports. The authors are responsible for the accuracy and completeness of the references

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B. When writing a reference in text, the surname of the author should be given; if there are two authors, the surnames of both the authors should be given & if there are more than two authors, then surname of first author followed by "et al" and name(s) should be followed by year in bracket.

C1. Books: Author's surnames and initials of first name; name of chapter (if any). In: full title of the book; Edition; Name & Domicile of Publisher; Year of Publication; pp (first & last page no.) eg. Weiner JS. Human Biology, an introduction to human evolution, variation & growth. In: Human Ecology. W.A. Harrison, J.S. Weiner & N.A. Barnicat (Eds,), Ist edition, Oxford University Press, Philadelphia, 1964; pp 401-508.

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Chapter of Neuro Developmental Pediatrics

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