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Evaluation of a nurse-led counselling intervention on selected outcome variables for parents of children with congenital adrenal hyperplasia

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Abstract

Objectives: Long-term care of children with Congenital Adrenal Hyperplasia (CAH) has psycho-social implications for parents. Experts recommend a customized educational program for parents to facilitate their psychological adaptation and improve disease management. Such educational programs often provided by nurse counsellors are well evaluated in developed countries. There is a dearth of data on nurse-led counselling in the context of less developed countries. We aimed to evaluate the effect of a nurse-led counselling intervention on various psycho-social outcomes among parents of children with CAH.

Methods: Fifty consecutive parents of children with CAH attending an outpatient clinic at a tertiary-care teaching hospital were enrolled. Parents' stress level, stigma, knowledge, practices, and treatment adherence were assessed by using Cohen's Perceived Stress Scale (PSS), DSD Stigma scale, and HILL-Bon Medication Adherence Scale (HB-MAS). Three educational counselling sessions were conducted within a month's gap, using PowerPoint presentations and a booklet. Assessment of outcomes was done at baseline and at the end of the third session.

Results: At baseline, the majority (90%) of the parents had moderate stress. Half of the parents had mild and the rest

had moderate stigma. After the intervention, the majority (94%) of parents had shifted to mild levels of stress and stigma. At baseline, 86% of the parents had poor knowledge about the disease whereas post-intervention, 80% were having good knowledge. Disease management practices and treatment adherence also improved after the intervention.

Conclusions: Nurse-led counselling was effective in reducing psycho-social problems, increasing knowledge, as well as improving practices and treatment adherence.

Keywords: CAH; knowledge; parental counselling; practices; psycho-social; treatment adherence.

Introduction

Congenital Adrenal Hyperplasia (CAH) is an autosomal recessive disorder that disrupts adrenal steroidogenesis, leading to a variety of symptoms in both boys and girls [1]. It is also the commonest cause of peripheral precocious puberty in our region [2]. CAH is further categorized as classical and non-classical forms. The classic CAH is a more severe form and, if not detected and treated, may result in adrenal crisis and death. It is further sub-categorized as salt-wasting (SW) and simple-virilizing (SV) forms. A child with SW CAH needs lifelong hormonal (glucocorticoid and mineralocorticoid) replacement and additional cortisol during times of illness, stress, or injury. Female children born with classical CAH have ambiguous genitalia due to the effect of excess androgens, which often need surgical correction along with hormone replacement. Thus, the diagnosis of CAH requires life-long care and involves a significant financial burden [3]. Diagnosis of CAH in a child lowers the quality of life of both the child and the parents [4].

Very few parents (10%) have adequate knowledge and awareness about the disease and its management [5]. This leads to many psycho-social implications including stress [6, 7]. Such stress clubbed with myths, misconceptions and the existing social stigma related to disorders of sexual development (DSD) often result in practices potentially harmful to these children [8]. Experts have often emphasized providing written information in an easy and understandable language for these parents [9]. A recent literature review on family

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educational strategies for children diagnosed with CAH recommended that educational interventions should be individualized based on the parent's emotional state and literacy level. The learning style, amount of information to be given, and mode of assessment should be then decided accordingly [10]. Hence, a specialized nurse educator can play a significant role in ensuring the effectiveness of a multidisciplinary approach for these patients and the affected families [11]. Such nurse-led counselling is a well-established component of CAH care in several Pediatric Endocrine centers in developed countries. However, its usefulness remains largely unevaluated in the context of a developing country set-up. The aim of our study was to evaluate the effectiveness of nurse-led counselling intervention on psychosocial problems, knowledge, practices, and treatment adherence among parents of children with CAH.

Methods

In this study, a pre-test post-test experimental study design was used. A consecutive sampling technique was used to enroll 50 parents of children with CAH (up to 12 years of age) who were attending the Endocrinology Clinic in a tertiary pediatric hospital in North India. The ethical approval for the study was obtained from the Institute Ethics Committee (Ref no. INT/IEC/2021/SPL-1017 dated 02/07/2021) and the study was registered with the Clinical Trials Registry of India (CTRI/2021/07/034784, dated 12/07/2021). Written informed consent was taken from all the participants prior to enrollment. Parents of children who had any other genetic/medical condition along with CAH were excluded from the study.

Standardized tools were used to assess the stress, stigma, and treatment adherence; Cohen's Perceived Stress Scale (PSS) (English [12] and Hindi [13]), DSD Stigma scale [14] and Hill-Bone Medication Adherence Scale [15] (HB-MAS), respectively. To assess the knowledge and practices, a questionnaire was developed and validated by various experts from the field of Nursing, Pediatrics, and Psychiatry. Socio-demographic data were collected as per the BG Prasad scale [16].

The PSS is a ten-item questionnaire and its responses range from 'Never' to 'Very often' on a five-point Likert Scale. The maximum score is 40; sub-categorized as (0–13) low stress, (14–26) moderate stress, and (27–40) high perceived stress. The DSD stigma scale is also a five-point Likert Scale ranging from 'Never' to 'Almost all the time'. It is an 11-item questionnaire but permission was obtained to use only seven relevant items. The maximum score is 35 which is sub-categorized as severe (>28), moderate (18–28), and mild stigma (<18). The HB-MAS is a nine-item questionnaire. It has four options on a Likert Scale ranging from 'All the time' to 'None of the time'. The maximum score is 36; sub-categorized as poor adherence (<18), moderate adherence (18–29), and good adherence (>29). The knowledge questionnaire had ten multiple choice questions with only one correct answer among four options. The maximum score is ten; subcategorized as good (>8), moderate (5–8), and poor knowledge (<5). The practice questionnaire had eight questions related to management practices followed at home. An information booklet on 'management of CAH at home' was developed after consultation with various experts from the field of pediatrics, psychiatry, and nursing. It included

the following topics—CAH, causes, types, diagnostic measures, treatment options, adrenal crisis—symptoms and management, and prevention of CAH. The booklet was translated into the Hindi language for easy understanding of parents and was validated by two experts. The information was also converted into a PowerPoint Presentation (PPT) in the Hindi language to be used as an educational aid during the counselling.

After a baseline assessment of the outcome variables, three sessions of individualized counselling were conducted; each at an interval of one month. In the first session, parents were provided complete information about the disease using the PPT. The booklet was given to the parent for reading at home. After one month, the second session was conducted similarly. Parents who came to the clinic after a month for follow-up were counselled physically (n = 10, 20%) and the rest were counselled telephonically (n = 40, 80%). The opportunity to clear all their queries was given at all counselling sessions. Again after one month, the third and final session (70% of parents counselled telephonically and 30% physically) was conducted, which was followed by an assessment of outcome variables.

Statistical analysis

The data collected was analyzed using SPSS software for Windows (version 20.0; SPSS Inc., Chicago, Illinois). Demographics of parents and children, stress, and stigma were described in frequency, percentage, mean and standard deviation. Knowledge and treatment adherence were described as median and Inter Quartile ranges (IQR). A Correlation coefficient based on the distribution of data was used to find the relationship between various outcome variables. Pre and post-intervention data were compared depending on the normality of the data. As stress and stigma variables were normally distributed, their means were compared by paired *t*-test. Knowledge and treatment adherence were not normally distributed, so their medians were compared by Wilcoxon signed-rank test. A *p*-value of less than 0.05 was taken as significant.

Results

Table 1 shows the socio-demographic profile of the participants. An equal number of mothers and fathers (50%) participated in the study, and the age range was 31–40 years. An almost equal number of mothers and fathers were educated up to senior secondary level and above. Almost all the mothers (98%) were housewives and 68% of the fathers were unskilled workers and were engaged in private jobs. The majority of the parents (72%) belonged to the Hindu religion, joint family (62%), and upper middle class (62%). A total of 54% of the parents belonged to rural habitats.

Fifty-eight percent of children were less than 5 years of age (median age 57 months, IQR 20.25–84 months). At the time of the study, 50% of the children were boys. But at birth, respectively, 56, 22, and 22% were assigned male, female, and ambiguous gender. Few children (8%) had a history of siblings

Table 1: Socio-demographic profile of parents of children with CAH.

Variables	Frequency, %
Relation with the child	
Father	25 (50%)
Mother	25 (50%)
Age of mothers, years	
Mean \pm SD (range)	31.26 \pm 5.26 (22–47)
21–30	24 (48)
31–40	24 (48)
>40	2 (04)
Age of fathers, years	
Mean \pm SD (range)	34.40 \pm 5.81 (24–49)
21–30	14 (28)
31–40	26 (52)
>40	10 (20)
Educational qualifications (fathers)	
Matriculation	13 (26)
Senior secondary	21 (42)
Graduation & above	16 (32)
Educational qualifications (mothers)	
Matriculation	14 (28)
Senior secondary	19 (38)
Graduation & above	17 (34)
Occupation (fathers)	
Unskilled	34 (68)
Skilled	1 (02)
Professionals	13 (26)
Any other	2 (04)
Occupation (mothers)	
Professionals	1 (2)
Housewives	49 (50)
Religion	
Hindu	36 (72)
Sikh	9 (18)
Muslim	5 (10)
Family type	
Nuclear	19 (38)
Joint	31 (62)
Per capita income (as per BG Prasad scale)¹⁶	
>7770	11 (22)
3808–7769	31 (62)
2253–3808	7 (14)
<1166	1 (02)
Residence	
Urban	23 (46)
Rural	27 (54)

also having CAH. The majority (82%) of the children had SW CAH, and 66% were diagnosed within a month of their life.

Figures 1 and 2 depict the stress and stigma levels of the parents, respectively. At baseline, a majority (90%) of the parents had a moderate stress level whereas after the intervention, the majority (94%) had shifted to the mild stress category. Similarly, 50% of the participants had a mild level of stigma, and the rest 50% were having a moderate level of stigma at baseline, whereas after the intervention, all the participants had only a mild level of stigma.

Table 2 depicts the knowledge level of the parents. At baseline, the median knowledge score was 2.50 (IQR 1–4) which improved to 9 (IQR 8–10) post-intervention. Initially, the majority (86%) of the parents had poor knowledge and others (14%) had a moderate level of knowledge. But after the intervention, 80% of the parents had good knowledge and 20% had moderate knowledge.

Table 3 shows the practices of parents regarding the management of the disease of their child. None of the parents had used any other treatment method apart from glucocorticoids and mineralocorticoids. At baseline, only 6% of parents responded that they were aware of sick days/adrenal crises, which improved to 100% after the intervention. In response to the symptoms of adrenal crisis at the baseline, refusal to feed was reported by 4% of parents, loss of appetite by 4%, vomiting by 6%, and diarrhea by 6% of parents which improved to 44, 22, 100, and 100% respectively after the intervention.

Table 4 represents treatment adherence among the participants. The treatment adherence was found to be good even at baseline. But there was a significant improvement in three out of nine items of HB-MAS. In item 1 – ‘how often they forgot to give prescribed medicines to their child’, at baseline 24% of the parents responded ‘some of the time’, whereas after counselling only 2 % of the parents responded so. In item 2 ‘how often do they decide not to give prescribed medicines to their child?’ – 16% of parents responded ‘some of the time’, but after counselling, no parents responded so. In item no. 9, ‘how often they miss giving CAH medicines to their child when they are careless’ – 20% of parents responded that ‘some of the time’, which reduced to 6% after the intervention. Overall, the median score of treatment adherence (IQR) at baseline was 35.5 (34–36) which significantly ($p=0.001$) improved to 36 (36–36) after the intervention.

Further, the outcome variables were assessed for correlation with each other. The stress and stigma levels positively correlated ($r=0.36$) with each other significantly ($p\text{-value}=0.09$). Also, stress level negatively correlated with knowledge ($r=-0.32$, $p\text{-value}=0.02$). The stress level was also found to be negatively correlated with the age of the father ($r=-0.30$, 0.03). None of the other outcome variables correlated with any of the socio-demographic variables.

LEVEL OF STRESS AMONG PARENTS PRE AND POST INTERVENTION

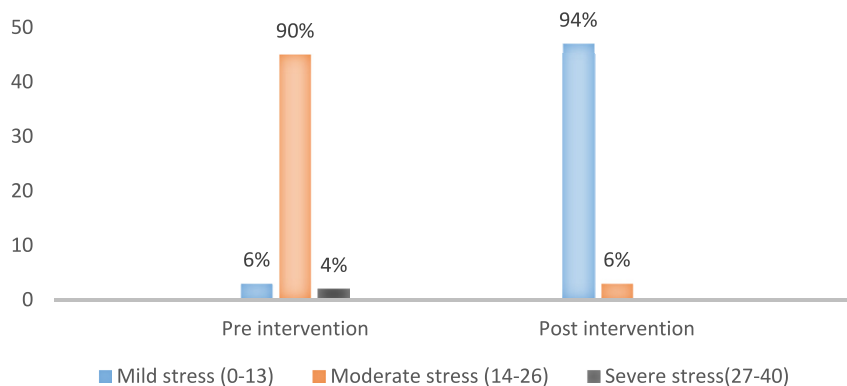


Figure 1: Change in stress level after intervention among parents.

LEVEL OF STIGMA AMONG PARENTS PRE AND POST INTERVENTION

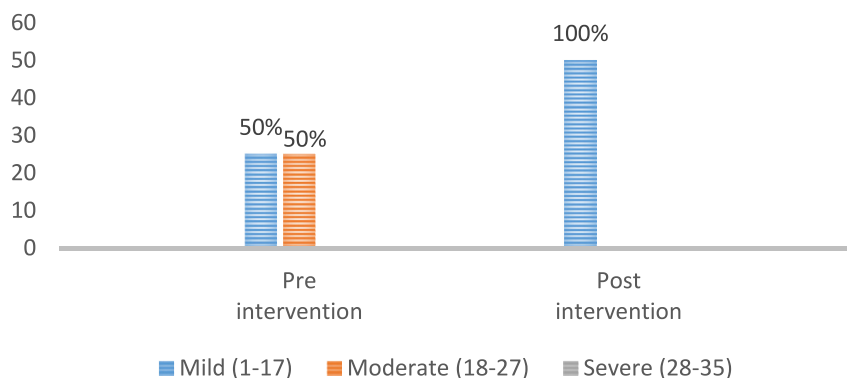


Figure 2: Change in stigma level among parents after intervention.

Table 2: Change of knowledge of parents after intervention (n=50).

Knowledge level	Pre-intervention, %	Post-intervention, %
Poor (0–4)	43 (86)	–
Moderate (5–8)	7 (14)	10 (20)
Good (9–10)	–	40 (80)
Median knowledge score Q1–Q3	2.50 (1–4)	9 (8–10)

Discussion

This study found satisfactory effects of a nurse-led counselling intervention on psycho-social problems, knowledge, practices, and treatment adherence among parents of children with CAH. Although the existing literature provides the prevalence of poor knowledge, high stress, low awareness, and treatment adherence among parents of children with CAH [7, 17]. Only one previous study has reported using a Psychosocial Education Program for families with a child having CAH [18]. Hence,

the present study provides much-needed evidence that such educational counselling interventions by nurses for parents of children with CAH can be very useful.

In the present study, 90% of parents reported having moderate stress, and it was found to be related to poor knowledge about the disease. These findings are similar to previous studies [19, 20]. Regarding the stigma levels, the results are similar to earlier studies which reported moderate to high levels of stigma among parents of children with DSD including CAH [14]. The stigma has also been related to a persistent worry about the future of the affected child among the parents [21]. The traditional countries tend to stigmatize such disease conditions more than the developed nations [8, 22]. The positive correlation of stress with stigma points to the need to increase health awareness among the Indian population.

In the present study, although some parents were found to have certain erroneous practices related to regular follow-up and handling of adrenal crises, none of the parents reported using any medicinal system other than glucocorticoids and mineralocorticoids. However, misconceptions and knowledge

Table 3: Practices of parents regarding the management of disease of their child pre-and post-intervention.

Item	At baseline	After intervention	p-Value ^a
Have they ever used or are using any treatment methods other than glucocorticoids and mineralocorticoids?	–	–	–
If yes, please specify which medicine	–	–	–
Are they aware of the sick day symptoms/adrenal crisis	3 (6)	50 (100)	<0.01
If yes, please tick the symptoms (can tick more than one) ^a			
Refusal to feed	2 (4)	22 (44)	<0.01
Vomiting	3 (6)	50 (100)	<0.01
Diarrhea	3 (6)	50 (100)	<0.01
Loss of appetite	2 (4)	11 (22)	<0.01
Low B.P.	–	11 (22)	0.01
Dizziness	–	31 (62)	<0.01
Fit/seizure	–	24 (62)	<0.01
What will they do after seeing these symptoms?			
Visit a doctor	33 (66)	–	<0.01
Increase the dose of prescribed medicines	8 (16)	50 (100)	
Not sure	9 (18)	–	
When do they take their child to the doctor			
Whenever they want to	5 (10)	–	<0.01
Whenever called for regular follow-up	38 (76)	50 (100)	
Not sure	7 (14)	–	
Have they ever stopped the medicine of the child	2 (4)	–	0.50
If yes, please specify the reason			
Due to economic reasons	2 (4)	–	0.50

^aMcNemar test.

gaps about follow-ups, outcomes, and practices among the parents have been reported in a previous Indian study. A communication gap between them and their healthcare provider was reported to be one of the major reasons behind knowledge gaps about follow-up care and practice [8]. Conversely, another study conducted among parents in the same region of the country found no myths or misconceptions related to the disease among the participants [19]. This suggests vast differences in the misconceptions related to CAH even within the same geographical region.

In the current study, treatment adherence was found to be good in all the participants at the baseline level. Improvement in the treatment adherence scores after the

intervention can be due to subjective bias among the parents. However, similar findings were reported by Ekblom K et al., that parent-reported adherence was better as parents feel the responsibility to give medicines when their children suffer from any chronic illness [23].

The counselling sessions provided a unique opportunity to understand the mental state of these parents. Parents of girl children often expressed worry about feminine genital reconstruction surgery. Many parents expressed concern about the future of their children, especially after marriage. A mother of a girl with ambiguous genitals expressed her disbelief by saying that this girl was not her child, as I am absolutely normal. During counselling, parents whose first child was affected by the disease were effectively told that they should immediately come to OPD whenever they conceive to get antenatal investigations done to rule out the disease in the fetus. By providing information in easy language, not only did they understand the disease but also the need for regular follow-up and treatment adherence.

Overall, the parents felt supported and heard during counselling sessions. They felt relaxed when they were told that with regular treatment their child can live an almost normal life. When one parent of a male patient was being shown PPT, and he was told about the sign and symptoms in the female child (ambiguous genitalia), he immediately told that his 2-week-old daughter also had the same features. This helped in investigating the child's condition before an adrenal crisis that may have arisen if not been diagnosed earlier.

A few parents also reported that their child's ambiguous genitalia was not noticed at the time of birth in the hospital by the attending healthcare workers. It was only after discharge that some of the family members noticed the abnormality. It was only then they took their child to a doctor. This emphasizes the need for education regarding CAH among various healthcare professionals in the region.

The social acceptance of children with ambiguous genitalia is poor in India and has led to the continuation of the age-old social practice of handing over such children to kinnars or hijras (transgender community) [24]. Many parents revealed that several people advised them to give their children to the 'hijra' community due to the ambiguous genitals of their children, but they preferred to get medical advice. Parents were still apprehensive about whether their child was a 'hijra' (third gender). They were counseled that their child's gender is clear after genetic karyotyping. Even though the practice of handing over children with ambiguous genitalia to the transgender community is less prevalent than before, it still continues in modern India [8, 19, 24]. Almost all parents expressed the financial burden of the disease related to medications, follow-up visits, and investigations.

Table 4: Treatment adherence as assessed by the hill-bone medicine-adherence scale.

Item	All the time, %	Most of the time, %	Some of the time, %	None of the time, %	p-Value ^a
How often do they forget to give prescribed medicines to their child					
Pre-test	–	–	12 (24)	38 (76)	0.01
Post-test			1 (2)	49 (98)	
They decide not to give prescribed medicines to their child?					
Pre-test	–	–	8 (16)	42 (84)	0.08
Post-test			–	50 (100)	
They forget to get prescriptions filled					
Pre-test	–	–	5 (10)	45 (90)	0.06
Post-test			2 (4)	48 (96)	
They run out of the CAH pills					
Pre-test	–	–	7 (14)	43 (86)	0.18
Post-test	–	–	2 (4)	48 (96)	
They skip medicines before they go to the doctor					
Pre-test	–	–	–	50 (100)	–
Post-test	–	–	–	50 (100)	
They miss giving medicines when their child feels better					
Pre-test	–	1 (2)	6 (12)	43 (86)	0.16
Post-test	–	–	–	50 (100)	
They miss giving CAH medicines to their child when he/she feels sick					
Pre-test	–	–	–	50 (100)	–
Post-test	–	–	–	50 (100)	
They give someone else's medicines to their child					
Pre-test	–	–	–	50 (100)	–
Post-test	–	–	–	50 (100)	
They miss giving CAH medicines to their child when they are careless					
Pre-test	–	–	10 (20)	40 (80)	0.03
Post-test	–	–	3 (6)	47 (94)	

^aMcNemar test.

Our study thus confirms the usefulness of a nurse-led educational intervention in managing CAH in the context of a developing country. The intervention is effective, cheap, easy to implement, and may help improve long-term outcomes in children with CAH living in resource-limited settings. The study also emphasizes that the involvement of nursing staff is vital for effectively delivering healthcare to children with chronic disorders in a developing country [25].

Limitations

A limitation of this study is the lack of long-term outcomes assessment, especially for treatment adherence and follow-up. Even though parental knowledge improves after

educational interventions, they may still fail to do what is correct. An assessment of what parents actually do is therefore important which our study did not assess.

Conclusions

Parents of a child with CAH must accept the implications of this disease; the requirement of life-long treatment and the threat to life if not treated adequately. A nurse educator or counsellor may play a crucial role in providing the required knowledge and emotional support throughout the entire management process. An essential component of any such counselling or educational intervention will be recognition and acceptance of the parent's capability to understand and accept what is being told. The results of this study show that

nurse-led counselling was effective in reducing psychosocial problems, increasing knowledge, correct practices, and treatment adherence among parents of children with CAH. Therefore, nurses should be educated about CAH and the significance of counselling. Specialized and trained nurse educators/counsellors can be appointed in the Endocrinology outpatient units for educating the patients/parents of children with CAH.

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Author contributions: PV: literature search, selection of tools, making final booklet, data collection, data analysis and preparation of first draft. SK, SS and DD: study design, selection of tools, making final booklet, validation of data interpretation and intellectual inputs during the whole process. LR: booklet review and preparation of final draft of manuscript, PM: intellectual inputs in selection of tools and conducting counselling sessions, DD: preparation of final draft. All authors approved the final version of manuscript.

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