Paediatric Neurology Patients: Parental Awareness of Adverse Effects of Long-term Corticosteroid Therapy

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Research article

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Abstract

Background: Corticosteroids are potent medications used to treat in many inflammatory conditions in paediatric neurology practice. Although corticosteroids are beneficial, their adverse effects may be numerous and vary. As parents are the primary caregivers of paediatric patients, assessing their awareness is timely important.

Methods: To determine the parental awareness on adverse effects of corticosteroid therapy in Paediatric Neurology Patients in the Neurology Unit at the Lady Ridgeway Hospital, Colombo, Sri Lanka. In this descriptive cross-sectional study, 300 parents of paediatric neurology patients on long-term corticosteroid therapy in the paediatric neurology unit were included. Parents were volunteered for the study and signed informed consent. Ethical approval was obtained from the Ethics Review Committee of the same hospital. Data were collected using content validated, pre-tested self-administered questionnaire during January to March 2020.

Results: Of the total parents, the majority were mothers (87%, n=262) and more than 70% (n=211) of them completed their secondary education. Findings demonstrated that parents had average awareness about adverse effects of long-term steroid therapy including child’s susceptibility to infections (69.0%, n=207), increase blood glucose levels (69.7%, n=209), moon face (60.3%. n=181), central obesity (60.3%, n=181), increase blood pressure levels (58.0%, n=174) and (irritability 50.3%, n=151) while poor awareness on adverse effects include buffalo humps (26.7%, n=80) increase fracture tendency (24.3%, n=73), tarry colour stools (24.3%, n=73), vision impairment (24.0%, n=72), glaucoma (17.3%, n=52), cataract (16.0%, n=48 ) and delayed wound healing (23.0%, n=69). According to the findings, overall mean (SD) knowledge percentage on parental awareness of adverse effects was found to be low (38.24 ± 20.57).

Conclusion: Since parental awareness of the adverse effects of long-term corticosteroid therapy is inconsistent, special attention is needed to plan and implement appropriate awareness sessions.

Background

Paediatric neurology or child neurology refers to a special branch of medicine that deal with the management of neurology condition in neonates, infants, children and adolescent. The discipline of paediatric neurology encompasses diseases and disorders of the brain, spinal cord, peripheral nervous system, autonomic system, muscle and blood vessels that effects individual in this age group. Over the past two decades, high-dose of corticosteroids therapy (an approach already used to treat several neurological syndromes such as multiple sclerosis) has been used in various studies in the field of epilepsy in order to avoid the development of adverse effects and maintained long term efficacy [1-4]. In the USA in 2019, corticosteroids were the most common specific cause for drug-related adverse effects, accounting for 10.3% of all drug related adverse effects and 141,000 hospital stays [5].
Most of the neurological conditions among children are more common in clinical practice and are chronic and frustrating to parents. Recent evidence shows that corticosteroids which are synthetic drugs that closely resemble cortisol, a hormone that our body produce naturally, (Prednisolone, Methylprednisolone and Adrenocorticotropic) have been used extensively to treat many of these neurological conditions (auto immune diseases, epilepsy) due to their anti-inflammatory and structural effects. Furthermore, Global literature reveal that, a major concern related corticosteroid, especially in children and adolescents, is the possible development of adverse effects. The most frequent ones are excessive weight gain, hyperphagia, water retention with oedema, cushingoid appearance, hypertension, behavioural disturbances, increased infection susceptibility, electrolyte disturbances, hyperglycaemia, glycosuria, impaired glucose tolerance, frank diabetes, and sleep disorders. Furthermore, long term adverse effects such as hypothalamus-pituitary axis suppression, psychosis, osteoporosis, nephrocalcinosis, brain atrophy, cataracts and, in children growth retardation, have also been reported [6-9].

Although corticosteroids are beneficial medication in paediatric neurology practice. Prolong use (more than six month) of high doses of corticosteroids are associated with number of adverse effects; affecting various systems of the body such as immune, musculoskeletal. Ocular, dermatological, central nervous, endocrine, cardiovascular and gastrointestinal system. According to the study done in Italy on topical steroids (TCS) it reveals that topical corticosteroids (TCS) phobia is widespread among Italian families of children with Atopic dermatitis. Fear of TCS is associated with fear of applying too much cream, thus increasing the risk of poor compliance and treatment failure. That study highlighted that therapeutic education of the parents should need to be implemented.

Children are more vulnerable to those adverse effects than adult and therefore especial attention and care is needed to prevent adverse effects among paediatric neurology patients. Because majority of paediatric neurology patients receive corticosteroids on long term basis. Lack of parental awareness of adverse effects and their preventive measures may significantly attribute to limiting the success of preventing adverse effects of long-term corticosteroid therapy among paediatric neurology population and also lead to discontinuation of therapy. Corticosteroids usage prevalence in paediatric neurology population in neurology unit Lady Ridgeway Hospital (LRH) has increase significantly due to their therapeutic effect on some neurological conditions. This situation emphasizes the growing need of prevention of adverse effects of this potent medications while sparing the benefit of the treatment. Parental awareness plays a major role in identifying and prevention of such adverse events. Therefore, this study is attempted explore parental awareness of adverse effects and prevention of long-term corticosteroid therapy among paediatric neurology patients in neurology unit at LRH.

Methods

Study design
This was a quantitative descriptive cross-sectional conducted at the Lady Ridgeway Hospital for Children (LRH), Colombo, Sri Lanka. The tertiary care hospital is considered as the largest children's hospital in the world with a bed-strength of over 900. The study was conducted among parents attending to the neurology unit with their children for long-term steroid therapy. During 5th January and 31st March 2019. Purposive heterogeneous sampling technique had been used in this study, which allow to obtain a representative sample by using a judgment, which will result in saving time and money. The study design was quantitative descriptive study design.

Sample size determination and sampling procedures

Three hundred parents (father or mother) of children with neurological diagnosis and receiving corticosteroids in long term basis in neurology unit at LRH were purposively recruited for this cross-sectional study. Parents with children age less than 14 years who had diagnosed for with neurological disorder and on corticosteroids for long-term basis at the neurology unit were recruited for this study.

Study instrument and Data collection

Data was collected using structured questionnaire which was developed after reviewing literature and by obtaining inputs from clinical medical experts. It was consisted with three sections and only the second section (secondary data from clinic books) filled by investigators and the rest was filed by parents. The first section was filled with socio-demographic information of the parents. The second section comprised eight parts with 23 questions which were focused on assessment of parental awareness of corticosteroid adverse effects. Third section was included 18 items to assess parental awareness of preventive measures of cortico-steroid adverse effects. Questionnaire were initially developed in English and then translated in English and Tamil and it was administered considering parents preference medium. Content validity of the questionnaire was ensured by clinic and research experts. Questionnaire was pre-tested among 10 parents who did not involve in the study and finalized with incorporating comments received during the pre-test. Data were collected during 5th January and 31st March 2019. In general, 15-20 questionnaires were filled during a day without disturbing parents their clinic routines (Please refer the additional file – questionnaire in the supplementary section). Clarifications were Continuous follow up and supervision by the supervisors and principal investigators occurred throughout the data collection period.

Limitation of data collection

There were some limitations of data collection such as children were not given specific diagnosis for their disease, parents with most aggressive children could not fill the questionnaire, some children accompanied by their relations and guardians, faraway parent refuse to fill questionnaire because concern about time and more children with short term corticosteroid therapy. In addition to that
researchers expect participation of equal number of both parents. Unfortunately, this did not occur during data collection period. Fathers participation is very less when compared with mother’s participation.

**Ethical consideration**

Ethical clearance was obtained from Ethics Review Committee of the Lady Ridgeway Children Hospital, Sri Lanka, with the permission to conduct the research at neurology unit. When the inclusion criteria were met, participant given the information letter which was in Sinhala, Tamil or English. Written consent was taken prior to the study from the participants who was willing to accept. Privacy and confidentiality preserved throughout the study. Personal details were not been mentioned. A code given for each record. Data collection done without hindrance for the participants day to day activities. There were no any risks for the individual subject.

**Data analysis**

After collecting data from the subject, the investigators prepare the data for analysis. In this study the data were prepared according to above data preparation by using software such as Microsoft excel and Statistical Package for the Social Science (SPSS) version 18 [10].

**Results**

In this study questionnaire had 65 questions with some data views and variable views. According to the answers of questionnaire, researchers given marks as bellow, Yes-1 mark, No-0 mark, Don’t know-0 mark. After that answer no and don’t know considered together.
| Characteristic          | Frequency (%) |
|------------------------|---------------|
| **Parent**             |               |
| Male                   | 262(87.3)     |
| Female                 |               |
| **Age (in years)**     |               |
| <18                    | 8(2.7)        |
| 18-30                  | 41(13.7)      |
| 31-40                  | 165(55.0)     |
| 41-50                  | 71(23.7)      |
| 51-60                  | 15(5.0)       |
| **Marital Status**     |               |
| Married                | 295(98.3)     |
| Single                 | 1(0.3)        |
| Divorced               | 3(0.7)        |
| Widowed                | 2(0.7)        |
| **No of Children**     |               |
| One                    | 75(25.0)      |
| Two                    | 138(46.0)     |
| Three                  | 79(26.3)      |
| Four                   | 6(2.0)        |
| Five                   | 2(0.7)        |
| **Ethnicity**          |               |
| Sinhalese              | 267(89.0)     |
| Tamil                  | 8(2.7)        |
| Muslim                 | 21(7.0)       |
| Other                  | 4(1.3)        |
| **Education Level**    |               |
| Not school attend      | 1(0.3)        |
| Completed primary | 10(3.3) |
|-------------------|---------|
| Grade 6-11        | 46(15.3) |
| Ordinary Level    | 117(39.0) |
| Secondary Level   | 94(31.3) |
| Professional Course | 17(5.7) |
| Degree            | 15(5.0) |

**Employment**

|                      |        |
|----------------------|--------|
| Government           | 29(9.7) |
| Private              | 21(7.0) |
| Business             | 18(6.0) |
| Labor                | 9(3.0)  |
| Other                | 9(3.0)  |
| Non employed         | 214(71.3) |

**Monthly income (SLR)**

|             |        |
|--------------|--------|
| <12,000      | 20(6.7) |
| 12,000-20,000| 56(18.7) |
| 20,001-30,000| 84(28.0) |
| >30,000      | 140(46.7) |

Then the marks converted into the percentage. Study consisted of three hundred parents of paediatric neurology patients with long term corticosteroid therapy. The results were reported in terms of describing characteristics of the study sample. When finding socio-demographics characteristics in the study sample; mothers were accompanied their children most (87.3%). Most of them were in between 31-40 years (55.0%) of age and most of them have another child also 46.0%. According to the ethnic distribution of the sample, 89.0% were Sinhalese. Participating percentage of working parents were 28.7% (Table 1).

### Association between socio-demographic characteristics and parental awareness of adverse effects of corticosteroid therapy

Association between social–demographics characteristics and parental awareness of adverse effects of corticosteroids are shown in Table 2. Accordingly, there were statistically significant association between...
number of children in a family \( p = 0.049 \) and ethnicity \( p = 0.000 \) with the parental awareness of the adverse effects of corticosteroids. However, there is no significance association between parental awareness of the adverse effects of corticosteroids and category of parent, parent’s age, educational level, employment status and monthly income.

### Table 2
Socio-demographic characteristics with parental awareness about adverse effects of long-term corticosteroid therapy

| Characteristic | Category | Awareness | \( p \) value |
|---------------|----------|-----------|--------------|
|               |          | Poor \( n(\%) \) | Good \( n(\%) \) |
| Parents       | Father   | 28(12.9)  | 10(12)       | 0.842 |
|               | Mother   | 189(87.1) | 73(88)       |       |
| Age           | \(<= 40 \text{ years} \) | 160(73.7) | 54(65.1) | 0.137 |
|               | \(>40 \text{ years} \) | 57(26.3)  | 29(34.9)    |       |
| No of Children| \(<= 2 \text{ children} \) | 161(74.2) | 52(62.7) | 0.049 |
|               | \(>2 \text{ children} \) | 56(25.8)  | 31(37.3)    |       |
| Ethnicity     | Sinhalese| 185(85.3) | 82(98.7)    | 0.000*|
|               | Others   | 32(14.7)  | 1(1.2)      |       |
| Education     | Up to (O/L) | 130(59.9) | 44(53)      | 0.279 |
|               | Above (A/L) | 87(40.1)  | 39(47)      |       |
| Employment    | Yes      | 57(26.3)  | 29(34.9)    | 0.137 |
|               | No       | 160(73.7) | 54(65.1)    |       |
| Income(Monthly)| \(<= \text{SLR 30,000} \) | 119(54.8) | 41(49.4) | 0.398 |
|               | \(>\text{SLR 30,000} \) | 98(45.2)  | 42(50.6)    |       |

* \( p \)-value obtained from Fishers exact test Significance - \( p<0.05 \); (\( p \)-value = Pearson chi-square value).

### Parental awareness of corticosteroid adverse effects

In this part questionnaire consist of eight parts with 23 questions. Findings of the study shows parents have more experience and awareness about adverse effect of increase hunger 73.3\% (\( n = 220 \)), child’s susceptibility to infections 69.0\% (\( n = 207 \)), increase blood glucose levels 69.7\% (\( n = 209 \)), moon like face 60.3\% (\( n = 181 \)), central obesity 60.3\%(\( n = 181 \)), increase blood pressure levels 58.0\% (\( n = 174 \)) and irritability 50.3\% (\( n = 151 \)) during long term corticosteroid treatment. Parent awareness about buffalo
humps 26.7% (n =80), increase fracture tendency 24.3% (n =73), tarry colour stools 24.3% (n =73), vision impairment 24.0% (n =72) and delayed wound healing 23.0% (n =69). Parental awareness about adverse effects like acne 19.7% (n =59), glaucoma 17.3% (n =52) and cataract 16.0% (n =48). Findings are shown in Table 3 and Figure 1.
| Category                          | Correct n (%) | Incorrect n (%) | Awareness level % of categories |
|----------------------------------|---------------|----------------|---------------------------------|
| **Immune System**                |               |                |                                 |
| Steroid increase child’s susceptibility to infection | 207 (69.0)   | 93 (31.0)      | 69.0                            |
| **Endocrine and metabolism**     |               |                |                                 |
| Developing cushioned sign        | 181 (60.3)    | 80 (26.7)      | 51.3                            |
| Moon face’s                      | 119 (39.7)    | 220 (73.4)     |                                 |
| Buffalos hump central obesity    | 181 (60.3)    | 119 (39.7)     |                                 |
| Increase blood glucose level     | 209 (69.7)    | 91 (30.4)      |                                 |
| Increase blood cholesterol level | 99 (33.0)     | 201 (67.0)     |                                 |
| Increase blood pressure          | 174 (58.0)    | 126 (42.0)     |                                 |
| **Growth Suppression**           |               |                |                                 |
| Inhibit inner growth             | 4 (13.7)      | 259 (86.4)     | 13.7                            |
| **Dermatological side effects**  |               |                |                                 |
| Mild to moderate hair growth     | 117 (39.0)    | 183 (61.0)     | 30.14                           |
| Facial redness                   | 99 (33.0)     | 201 (67.0)     |                                 |
| Sweating                         | 108 (36.0)    | 192 (64.0)     |                                 |
| Acne                             | 59 (19.7)     | 241 (80.3)     |                                 |
| Delayed wound healing            | 69 (23.0)     | 231 (77.0)     |                                 |
| **Musculoskeletal**              |               |                |                                 |
| Increase tendency of fracture    | 73 (24.3)     | 227 (75.6)     | 24.3                            |
| **Behavioural changers**         |               |                |                                 |
| Lack of sleep                    | 102 (34.0)    | 198 (66.0)     | 44.3                            |
| Mood changers                    | 146 (48.7)    | 154 (51.3)     |                                 |
| Irritability                     | 151 (50.3)    | 149 (49.6)     |                                 |
| **Gastrointestinal**             |               |                |                                 |
| Increase hunger                  | 220 (73.3)    | 80 (26.7)      |                                 |
Continues crying 108 (36.0) 192 (64.0)
Nausea 106 (35.3) 194 (64.7)
Vomiting 93 (31.0) 207 (69.0)
Tarry colour stool 73 (24.3) 127 (75.6)

Changes in vision
Vision impairment 72 (24.0) 228 (76.0) 19.1
Cataract 48 (16.0) 252 (84.0)
Glaucoma (Eye pressure) 52 (17.3) 248 (82.7)

According to the findings, overall mean (SD) knowledge percentage on parental awareness of adverse effects was found to be lower (38.24 ± 20.57) and cannot be accepted as adequate. However, for the purpose of the study, knowledge on parental awareness on adverse effects on corticosteroid was categorized as good (≥ 50) verses poor (<50). Accordingly, 72.3% (n=217) of parents had poor knowledge and it was shown in Figure 2.

Parental awareness in preventive measures of corticosteroids’ adverse effects

Questionnaire consisted questions under eight categories with 18 questions to measure parental awareness of preventive measures of corticosteroids adverse effects (n=300) and findings are showed in Table 4 and Figure 3. According to the findings, the most of parents have knowledge to keep child away from crowded places (70.0%, n=217), and to take immediate medical advices if the child contact to chickenpox virus needed 67.0% (n=201). Higher proportion of parents knew the need of immediate medical if the child is suffering from fever, cough vomiting and diarrhoea (>86%) However, parental awareness prevent measures for fractures is very low (29.3%, n=88).
### Table 4
Parental awareness of preventive measures of cortico-steroid adverse effects

| Category                                    | Correct n (%) | Incorrect n (%) | Preventive awareness % |
|---------------------------------------------|---------------|-----------------|------------------------|
| **Immune System**                           |               |                 |                        |
| Prevent exposure to chickenpox              | 210 (70.0)    | 90 (30.0)       | 78.75                  |
| If contact to chickenpox get medical advice | 201 (67.0)    | 99 (33.0)       |                        |
| Need immediate medical care                 |               |                 |                        |
| Fever                                       | 273 (91.0)    | 27 (9.0)        |                        |
| Vomiting                                    | 263 (87.7)    | 37 (12.3)       |                        |
| Cough                                       | 259 (86.3)    | 41 (13.7)       |                        |
| Diarrhoea                                   | 264 (88.0)    | 36 (12.0)       |                        |
| Not exposure to crowd                       | 229 (76.3)    | 71 (23.6)       |                        |
| Should wear a mask                          | 191 (63.7)    | 109 (31.3)      |                        |
| **Endocrine and metabolic adverse effects** |               |                 |                        |
| Monitor fasting blood sugar                 | 160 (53.3)    | 140 (46.7)      | 63.52                  |
| Monitor serum electrolytes                  | 121 (40.3)    | 179 (59.7)      |                        |
| Monitor child’s weight                      | 149 (49.7)    | 151 (50.4)      |                        |
| Diet consist plenty of vegetables and fruits| 245 (81.7)    | 55 (18.3)       |                        |
| Diet should less                            |               |                 |                        |
| Starchy food                                | 218 (72.7)    | 82 (27.3)       |                        |
| Oily food                                   | 209 (69.7)    | 91 (30.3)       |                        |
| Sugar                                       | 232           | 68 (22.7)       |                        |
Growth retardation

| Monitoring height          | 155 (51.7) | 145 (48.4) | 51.7 |

Dermatological adverse effects

| Skin changers disappear with withdraw of steroids | 105 (35.0) | 195 (65.0) | 30.14 |

Muscular skeletal adverse effects Medical advice to prevent fractures

| Essential to give calcium | 138 (46.0) | 159 (54.0) | 37.66 |
| Essential to give vitamin D | 88 (29.3) | 212 (70.7) |

Fluid and electrolytes

| Blood pressure monitor 14 days is essential | 157 (52.3) | 143 (58.6) | 51.66 |
| Diet should consist with low salt | 153 (51.0) | 147 (49.0) |

Gastrointestinal adverse effects

| Give steroid ½ hour after administer antacid | 110 (36.7) | 190 (63.3) | 45.16 |
| Seek medical advice when tarry stool is present | 161 (53.7) | 144 (46.3) |

Prevention of adverse effects to eye

| Medical advice to check cataract and glaucoma | 163 (54.3) | 137 (45.6) | 54.33 |

According to the findings, overall mean (SD) percentage on parental awareness of preventive measures of adverse effects of corticosteroids was 61.86 ± 22.52. For the purpose of the study, it was categorized as good (≥ 50) verses poor (<50) considering the mean value. Accordingly, 65.7% (n=197) of parent’s awareness of preventive measures was good (Figure 4).

Association between socio-demographic characteristics and parental awareness of preventive measures of adverse effects of corticosteroids

As shown in Table 5, there were significant associations between parental awareness of prevention of adverse effects of corticosteroids and their monthly income (p = 0.001) and adequacy of the income (p = 0.027).
Table 5  
Association between socio-demographic characteristics and parental awareness of preventive measures of adverse effects of corticosteroids

| Characteristic     | Category   | Awareness |          |          |          |
|--------------------|------------|-----------|----------|----------|----------|
|                    |            | Good n (%)| Poor n (%)|          |          |
| Parents            | Father     | 26(13.2)  | 12(11.7)  | 0.702    |          |
|                    | Mother     | 171(86.8) | 91(88.3)  |          |          |
| Age                | <= 40 years| 139(70.6) | 75(72.8)  | 0.681    |          |
|                    | >40 years  | 58(29.4)  | 28(27.2)  |          |          |
| No of Children     | <= 2 children| 135(68.5)| 78(75.7)  | 0.192    |          |
|                    | >2 children| 62(31.5)  | 25(24.3)  |          |          |
| Ethnicity          | Sinhalese  | 174(88.3) | 93(90.3)  | 0.605    |          |
|                    | Others     | 23(11.7)  | 10(9.7)   |          |          |
| Education          | Up to (O/L)| 108(54.8) | 66(64.1)  | 0.123    |          |
|                    | Above (A/L)| 89(48.2)  | 37(35.9)  |          |          |
| Employment         | Yes        | 89(29.9)  | 27(26.2)  | 0.497    |          |
|                    | No         | 138(70.1) | 76(73.8)  |          |          |
| Income (Monthly)   | <=SLR 30,000| 91(46.2)  | 69(67.0)  | 0.001    |          |
|                    | >SLR 30,000| 106(53.8) | 34(33.0)  |          |          |

(p-value = Pearson chi-square value).

**Discussion**

Corticosteroids have been the mainstay of management for more than a half-century [11]. Findings of this study show that parental awareness of corticosteroid adverse effects and preventive measure influence the continuation of their treatment of their children. Many studies have illustrated how patient attitude and knowledge effects the continuation of their children steroid therapy and this may reduce implication of hospital stay thus leading to economic benefit [12].

In this study it was shown that the majority of participants have poor awareness on adverse effects of long term corticosteroid therapy. Sample of 217 participants out of sample population of 300 demonstrated poor awareness of adverse effects of corticosteroids. Since the male and female participants sample were not comparable awareness mothers' verses fathers. These results were contrast with another study was done in Netherland, finding of that study have shown that parents' awareness of adverse effect was good [13]. A similar situation, in Arab Emirates, Al Lela et al., (2014) pointed out
parents’ awareness about it associated risks was poor. Most probable reason for Netherland study in contrast with our study[14], Netherland is developed country and they use new technology and educational method than Sri Lanka.

In this present research, there were statistically significant association of number of children in a family (p = 0.049) with the parental awareness of the adverse effects of corticosteroid. The parents who have less than two children had poor awareness about adverse effects of corticosteroid than the parents who have more than two children (p < 0.05). There were statistically significant association of ethnicity (p = 0.000) with the parental awareness of the adverse effects of corticosteroid. However, majority of people had less awareness regarding the adverse effects of corticosteroid (p < 0.05). There was no significantly association between educational level (p = 0.279), occupational participation (p = 0.137), monthly income (p = 0.398) the sufficiency of income level, age, height and clinical diagnosis for parental awareness of the adverse effects of corticosteroids. Because of their p value was high (p > 0.05).

According to the present study a significant proportion of participant had a better awareness of adverse effects of increase hunger 73.3%(n = 220), susceptibility to infection 69%(n = 207), increase blood glucose level 69.7% (n = 209), moon like face 60.3% (n = 181), central obesity 60.3% (n = 181), increase blood pressure level 58% (n = 174) and irritability 50.3% (n = 151). In contrast the awareness of long term steroid therapy such as buffalo humps 26.7%(n = 80), Increase fracture tendency 24.3%(n = 73), tarry colour stools 24.3%(n = 73), vision impairment 24%(n = 72) and delayed wound healing 23% (n = 69) during long term corticosteroid treatment was poor. The better awareness the adverse effects like increased hunger, moon like face attributed to the parents personal experience with their own children who were on long term corticosteroid therapy. Finding of present study revealed that parent was more awareness regarding side effect of increase hunger 73.3% (n = 220) than the others. There was a similar situation found in Netherland. According to them most frequent was change in taste (61%), facial flushing (61%), feeling sick or having stomach pain and disturbance(44%) (Jongen at al., 2010). Hungry and tasty is most common personal experience in among participant’s child. So that findings were similar in both the countries.

According to the findings of study, socio demographic data, monthly income (p = 0.001) and adequacy of the income (p = 0.027) were statistically significant associated with preventive measures of adverse effects of corticosteroids. The preventive measure for adverse effects of corticosteroid also related to family income of the people, who have more income (>Rs30000) had taken many preventive methods than the family’s low incomes. Parents (p = 0.702), age (p = 0.192), number of children (p = 0.605), ethnicity (p = 0.605), education level (p = 0.123) and employment (p = 0.497) were not statistically significant in association with the preventive measures about adverse effects of corticosteroids. In this study it was noticed that, majority of parents know that the child should kept away from crowded places 70%(n = 210), if contact to chickenpox virus need immediate medical advice 67% (n = 201). They also had vomiting 87.7%(n = 263), diarrhea 88%(n = 264), cough 86.3%(n = 259). May be the parents are scared regarding chickenpox of the their past experience with it. So, They are very concerning about taking preventing measure from chicken pox. This may be a reason for the above result.
In the present study, researcher identify they have less awareness about vitamin D Supplement that should be given to prevent fracture (29.3%). These results were contrasts with another study done in England. Chalitsios et al., (2020) pointed out that meta-analysis demonstrate a clinically statistically significant prevention of bone loss at lumbar spine and fore arm with vitamin D and calcium in corticosteroid treatment [15]. In UK, this study done about oral corticosteroid treatment for the prevention of osteoporosis. The study highlighted that large number of people in population who are taking continuous oral steroids and shows the preventive measures for osteoporosis, are being implemented frequently.

Findings of the present study highlighted preventive measure knowledge percentage of parental awareness of adverse effects was higher and can be accepted as adequate they have good preventive awareness. Result of parental preventive awareness was good 65.7% (n = 197). These results were contrasts with another study done in Morocco. This study done with long term glucocorticoids steroid hormone therapy. According to their result weight gain (27%) an out of (18%) patient reported episodes of treatment discontinuation [16]. It may be reason for poor knowledge about preventive measure of adverse effects of steroid therapy in Morocco.

Conclusions

In most neurological condition among children requiring treatment with corticosteroids in long term basis. This therapy cannot be replaced by any other. Usually, long term treatment with corticosteroids benefits outweigh the adverse effects, with time. However, complication of therapy may become burden for the children. In most cases, unable to give up treatment with long term corticosteroids and for that reason it is not possible to avoid the adverse effects. However, with increasing parental awareness of corticosteroid adverse effects and proper prevention methods they can be minimize or prevent. According to the findings of study conducted in LRH Neurology Unit overall parental awareness of adverse effects are poor and preventive awareness of adverse effects of long-term corticosteroid therapy are good. Therefore, special attention needed to increase parental awareness of adverse effects of long-term corticosteroid therapy.

Abbreviations

TCS- topical steroids/topical corticosteroids; LRH-Lady Ridgeway Hospital; SPSS-Statistical Package for the Social Science

Declarations

Ethics approval and consent to participate

Signed informed consent was obtained from all participants’ parents or legal guardians. Ethical clearance was obtained from Ethics Review Committee of the Lady Ridgeway Children Hospital, Sri Lanka, with the
permission to conduct the research at neurology unit.

Consent for publication

Not applicable.

Availability of data and material

The datasets used during the current study are available through the corresponding author on reasonable request and upon permission from the university and the hospital.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

PerUKC: Collected the data, SamJSEA: performed data analysis, ShiHWCK and MohWMD: interpreted the data, and wrote the manuscript. SriKA and FaiMMTM: Designed the study, involved in critical revision of the manuscript. All authors read and approved the final version of the manuscript.

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Figures
Figure 1

Parental awareness of adverse effects in different categories.
Figure 2

Parent's awareness about adverse effects

Parental preventive awareness level

Prevention of eyes
Gastrointestinal
Fluid electrolytes
Muscular skeletal side effect
Dermatology side effect
Growth retardation
Endocrine and metabolism
Immunity response

Percentage

Figure 3

Parental awareness of preventive measures of adverse effects of corticosteroids in different categories
Figure 4

Parental overall awareness of preventive measures of adverse effects of corticosteroids

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