

A Questionnaire Based Study on the Knowledge and Practice of Stress Steroid Dosing Protocol among Patients with Adrenal Insufficiency at a Tertiary Care Hospital in India

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Abstract

Introduction: Acute adrenal insufficiency or adrenal crisis (AC) has a mortality rate of 0.5 / 100 patient-years and is a major cause of death in patients with adrenal insufficiency (AI). Non-compliance to steroids and inadequate stress dosing of glucocorticoids can precipitate AC in subjects with AI. In this study we tried to assess the knowledge pertaining to the disease, stress dosing and practice among individuals with AI. **Methods:** Ninety-two subjects diagnosed with AI and visiting Endocrinology Outpatient Department (OPD) were subjected to a structured researcher administered questionnaire including questions on knowledge about the disease, symptoms of AI, stress dosing, and practice with respect to cortisol replacement therapy (CRT). **Results:** Of the 92 participants, 13% were ignorant of the symptoms of AC, while about 78.2% of the entrants were aware that the dose of glucocorticoid must be doubled during illness. Around 20.7% of the subjects had intermittently stopped therapy on their own, while 13% partakers had failed to increase dose of glucocorticoid during illness. Hospitalization for AC was seen in 18.5% of entrants since the initial diagnosis of AI, with the most common precipitating cause being infection (70.6%). **Conclusion:** There were lacunae in the knowledge about AC, CRT and stress dosing of glucocorticoids, and self-care among a significant number of patients with AI despite prior patient education. Hence, it is pertinent to reassess the knowledge, educate and reinforce good practices at multiple follow up visits to prevent AC and improve quality of life in individuals with AI.

Keywords: Adrenal crisis, adrenal insufficiency, cortisol replacement therapy, knowledge and practice, patient education

INTRODUCTION

Adrenal insufficiency (AI) is an endocrine disorder characterized by an absolute or relative deficiency of cortisol production.^[1] Acute AI or adrenal crisis (AC) is a life-threatening medical emergency affecting patients with AI which can be easily treated with glucocorticoids or CRT.^[2,3] In patients with AI, nonadherence to glucocorticoid therapy and conditions which increase cortisol requirement like concurrent infections, medical or surgical procedures, trauma and profound stress can precipitate AC.^[2,4] All patients with AI should be educated regarding the importance of compliance to glucocorticoids, and be equipped with a steroid emergency card to be carried with them at all times. They should also be informed regarding measures to prevent AC including oral stress dosing of glucocorticoids, involving doubling or tripling the glucocorticoid dose during illness and should be taught about self- injection of parenteral

hydrocortisone during emergency.^[4,5] The incidence of AC continues to be as high at 5–10 events per 100 patient- years, with a mortality rate of 0.5 per 100 patient-years.^[6] Patient education is the key to prevent AC. In this study we attempt to assess the knowledge about the disease and practice of stress dosing of glucocorticoids among patients with AI at follow up visit in an outpatient department at a tertiary care center in India.

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MATERIAL AND METHODS

Study design and participants

This was a questionnaire based cross-sectional study conducted in the Department of Endocrinology at a tertiary care hospital in India. All subjects with newly detected AI at our institute are educated about AI, symptoms of AC, daily dose, timing, importance of compliance to CRT, oral stress dosing of glucocorticoids, and situations where stress dosing must be followed. They are taught about subcutaneous (sc) self-injection of hydrocortisone injection (with insulin syringe after reconstitution with 1 ml sterile water) and are issued a steroid alert card [Figure 1] to be always carried by the patient. Subjects aged more than or equal to 18 years with primary AI (PAI) (Adrenal etiology of AI), secondary AI (SAI) (Pituitary etiology of AI) or exogenous glucocorticoid induced AI (GIAI), on follow up visit to endocrinology OPD or admitted in the ward on follow up, were included in the study. Nonconsenting subjects and newly diagnosed cases of AI were excluded.

Study tool

A structured questionnaire was prepared to assess the knowledge and practice of glucocorticoid stress dosing protocol in patients with AI. Each participant was interviewed face-to-face by the researchers. The questions were multiple choice questions or yes/no type questions. The questionnaire consisted of two sections with a total of 18 questions. The first section containing 12 questions assessed the “knowledge”, and the second section comprising six questions assessed the “practice” of patients regarding AI, its treatment, and stress dosing of oral glucocorticoid and sc injection of hydrocortisone. Information regarding the need for medical assistance or hospitalization for AC in the past, since the initial diagnosis was also collected.

The Cronbach alpha for the questionnaire to assess knowledge was 0.736, while the Cronbach alpha for the questionnaire to assess practice was 0.683. The Cronbach alpha for the entire questionnaire was 0.7, demonstrating acceptable internal consistency in responses.

Statistical methods and data analysis

Among patients with AI, to observe that 60% of the participants have knowledge with 10% precision and 95% confidence level, the minimum sample size required was calculated to be 92. Statistical analysis was done using descriptive statistics. Data was analyzed with the statistical package for the social sciences

(SPSS) software version 24.0. Continuous variables were presented as mean values \pm standard deviation (SD) or median value with range, while categorical variables were presented as percentages. To compare the responses to the questionnaire with the demographic characteristics, the independent *t* test was used for continuous variables, and the Chi-square test was used for categorical variables. All tests were considered significant at a 5% level of significance.

Ethical aspect

The study was approved by Institutional Ethics Committee (IEC) of St John’s Medical College and Hospital vide IEC study reference number 152/2019 on 23rd May 2019. A written informed consent was obtained for participation in the study and use of the patient data for research and educational purposes from all study participants. The procedures followed the guidelines laid down in the Declaration of Helsinki 1964 and as revised later.

RESULTS

Ninety-two participants with AI were included in the study. Among them, 58.7% (54) were males and 41.3% (38) were females. The median age of the participants was 46 years (range 18–85 years). Among them 30.4% (28) had PAI, SAI was seen in 53.3% (49), while 16.3% (15) of the participants had GIAI.

Knowledge about symptoms of AC and stress steroid dosing

Among the 92 participants, 96.7% (89) subjects confirmed that they had been explained about AI and informed regarding medication doses in illness. Nearly 85.9% (79) partakers felt glucocorticoid replacement is important for survival. However, only one individual could identify all the symptoms of acute AI or AC and the common situations requiring stress dosing of glucocorticoids. Around 13% (12) entrants were unaware of the symptoms of AC and 19.5% (18) participants were unknowing about situations requiring stress steroid dosing. Mild fever not requiring stress dosing was wrongly identified as a situation requiring stress dosing by 16.3% (15) of the subjects, while moderate to high-grade fever was correctly identified as requiring stress steroid dosing by 63% (58) of the partakers [Table 1].

About 78.2% (72) of the entrants were in the know of the need to double the dose of glucocorticoids during stress (stress steroid dosing), while only one participant was aware that the stress steroid dosing should be continued for the entire duration of illness. Of the 92 subjects, not more than 46.7% (43) were aware that glucocorticoid tablets should not be stopped during vomiting, while as little as 36.9% (34) individuals responded that they would administer injection hydrocortisone if they were unable to tolerate oral medications due to vomiting. Among the 28 subjects with PAI, 60.7% (17) knew that the fludrocortisone dose need not be increased during stress [Table 2].

Around 93.5% (86) of the entrants were aware that glucocorticoids should not be stopped without consulting

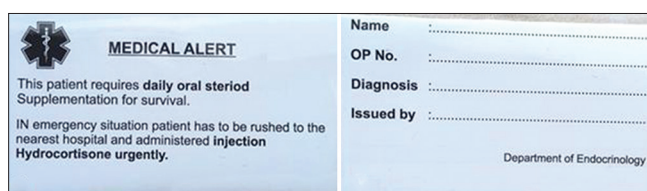


Figure 1: Steroid Emergency Card used at our hospital. a) Front of card. Information regarding the need for daily oral glucocorticoid and injection of hydrocortisone in emergency situations was mentioned. b) Back of card. Space is provided to enter patient details and diagnosis of the patient

Table 1: Awareness of symptoms of AC and knowledge about situations requiring stress dose (increases in dose) of glucocorticoid among participants

Questions administered to participants	Number of participants (%) who were aware of the symptom (n=92)	
What are the symptoms of low levels of blood cortisol hormone (AC)?		
a) Nausea, vomiting	46 (50)	
b) Loss of appetite	35 (38)	
c) Tiredness or severe fatigue	53 (57.6)	
d) Mild fever	11 (11.9)	
e) Giddiness or low blood pressure	23 (24.9)	
f) Abdominal pain	15 (16.3)	
g) Not aware	12 (13)	
In which of these situations should the dose of glucocorticoid (hydrocortisone/prednisolone) be increased?	Response frequency (%) among participants (n=92)	
	Yes	No
a) Mild fever (<38°C)	15 (16.3)	77 (83.7)
b) Moderate to high grade (>38°C) fever	58 (63)	34 (37)
c) Vomiting	38 (41)	54 (59)
d) Diarrhea/loose stools	26 (28.2)	66 (71.8)
e) Surgery/procedure	13 (12.1)	79 (87.9)
f) Not aware	18 (19.5)	

Table 2: Response of participants to questions regarding stress dosing of glucocorticoid in AC

Questions administered to participants	Response frequency (%) among participants (n=92)		
1) By how much should the dose of glucocorticoid be increased during stress?			
a) Need not be increased	1 (1.1)		
b) Increase by 2 times	72 (78.2)		
c) Increase by 4 times	0		
d) Increase by 1.5 times	1 (1.1)		
e) Not aware	18 (19.6)		
2) For how many days should the dose of glucocorticoid be increased?			
a) 1 day	3 (3.2)		
b) 2 days	14 (15.2)		
c) 3 days	4 (4.3)		
d) 1 week	43 (46.7)		
e) Duration of illness	1 (1.08)		
f) Not aware	27 (29.3)		
3) What should be done if there is vomiting?			
a) Continue to take glucocorticoid tablet	43 (46.7)		
b) Stop glucocorticoid tablet	0		
c) Take an injection of hydrocortisone	34 (36.9)		
d) Not aware	14 (15.2)		
e) Both a and c selected	1 (1.09)		
	Response frequency (%) among participants with PAI (n=28)		
	Yes	No	Not aware
4) Should the dose of fludrocortisone be increased during stress?	5 (17.9)	17 (60.7)	6 (21.4)

PAI – Primary adrenal insufficiency

their doctor. While 96.7% (89) of partakers confirmed that they had received steroid alert card [Figure 1] at diagnosis of AI, only 35.8% (33) of the participants could recollect self-administration technique for injection hydrocortisone.

Practice of participants with AI

Of the 92 subjects, 20.7% (19) of the participants had intermittently stopped therapy on their own, while 13%

(12) partakers had failed to increase doses during illness. Hospitalization for AC since the initial diagnosis of AI was documented in 18.5% (17) of the entrants. Of these only 11.7% (2) had self-administered or received injection hydrocortisone during illness or prior to procedure. The most common precipitating cause for AC was infection (70.6%), followed by non-compliance to medication (17.6%). About 88% (81) of the partakers informed that they carried the steroid alert

Table 3: Practices of participants with AI

Questions administered to the participants with AI	Response frequency (%) among participants (n=92)	
	Yes	No
Do you carry a steroid alert card when traveling out of the station?	81 (88)	11 (12)
Have you stopped treatment on your own?	19 (20.7)	73 (79.3)
Have you missed increasing the dose of medication during an illness?	12 (13)	80 (86.9)
Have you required hospitalization or medical care for symptoms of AI since initial diagnosis?	17 (18.5)	75 (81.5)
If yes, what was the precipitating event?	Response frequency (%) among participants (n=17)	
a) Respiratory infection	5 (29.4)	
b) Gastrointestinal Infection	1 (5.9)	
c) Other febrile infection	6 (35.3)	
d) Procedure	2 (11.8)	
e) Missed dose of medication	3 (17.6)	
If yes, have you taken an injection of hydrocortisone by yourself during the illness? or If yes, did you receive an extra dose of hydrocortisone before the procedure?	Response frequency (%) among participants (n=17)	
	Yes	No
	2 (11.7)	15 (88.3)

card [Figure 1] in person even while travelling out of station [Table 3].

Independent sample *t* test was conducted to compare the results of the questionnaire with variables like age, duration since diagnosis of AI and Chi-square test was used for the education levels of the participants. There was significant difference in the mean age of the partakers who failed to increase doses during illness [54.6 ± 12.5] and subjects who did increase dose during an illness (41.9 ± 15.5 ; *P* value = 0.029). Similarly, the mean age of those who failed to carry their steroid alert card (55.4 ± 9.7) was significantly different than the participants who carried their steroid alert card (41.4 ± 15.6 ; *P* value = 0.008). There was no significant association of the response to the questionnaire with duration since diagnosis of AI and education level of partakers.

DISCUSSION

CRT, which has been available since 1950 has significantly improved the longevity and quality of life of patients with AI.^[3,7] The daily cortisol production rate in adults and children is about 5–8 mg/m²/day which is approximately 10 mg/day. This is equivalent to oral hydrocortisone replacement dose of 15–25 mg/day, or prednisolone 3–5 mg/day.^[4,8] However, despite established replacement therapy, studies on patients with AI have revealed a high incidence of AC and a high mortality rate from AC.^[6] Patient education is an essential measure to improve the management of AI, prevent AC, and improve the quality of life. As there is no prior data on the knowledge and practice of stress steroid dosing among patients with AI in India, we assessed the same in our study.

Primary AI is rare, with a prevalence of 10–20 persons per 100,000 population, while SAI is relatively more common than PAI with a prevalence of 15–42 persons per 100,000 population.^[1,2] Hence based on the literature, the prevalence of PAI to SAI is around 1: 1.5 to 1:4. In our study, 30.4% (28)

had PAI while SAI was seen in 53.3% (64), the ratio of PAI to SAI being 1:2.8. Thus, our study sample is representative of the worldwide population of AI.

In healthy individuals, there is an increase in cortisol hormone production during critical illness, trauma, anesthesia, and surgery, with a great interindividual variation. In critical illness, enhanced cortisol production is necessary to prevent overshooting of immune response mechanisms (e.g. cytokine release) and resultant detrimental toxicity.^[4,9,10] In subjects with AI, these physical or emotional stressful conditions, or discontinuation of glucocorticoids could precipitate AC. In our study, out of 92 subjects with AI, about 14.1% (13) were unaware of the importance of CRT for survival. While 93.5% (86) of the entrants did know that glucocorticoid should not be stopped without consulting their doctor, about 20.7% (19) of participants had intermittently stopped CRT on their own.

Patients with AI should be made aware of the symptoms of AC like postural giddiness, nausea, vomiting, loss of appetite/anorexia, abdominal pain, limb or back pain, severe fatigue/tiredness, fever, somnolence, and impaired consciousness.^[3,6] On assessing knowledge about symptoms of AC among our subjects, 13% were ignorant about the symptoms.

In subjects with AI during febrile illness, glucocorticoid dose must be increased (stress dosing of glucocorticoid) to prevent AC. It is advised to double the daily dose (if fever >38°C) or triple the daily dose (if fever >39°C), until recovery of the illness [Table 4].^[4,6] Among our study participants, about 21.7% (20) were ignorant about the need for doubling the dose of glucocorticoid in illness, while only one patient was aware that stress steroid dosing must be continued for the entire duration of illness. During illness, 13% (12) of the participants failed to double the dose of CRT.

In a study by Kampmeyer *et al.*,^[11] none of the 33 patients who were interviewed could identify the need for adjustment

Table 4: Key educational points on hydrocortisone dose adjustment by patients in non-procedural stressful situations

	Condition	Suggested action to be taken by the patient with AI
1	Illness with fever >38°C	Double the hydrocortisone daily replacement doses until recovery. Subsequently, return to routine dose in 1–2 days. Increase intake of electrolyte-containing fluids as tolerated.
2	Illness with fever >39°C	Triple the hydrocortisone daily replacement doses until recovery. Subsequently, return to routine dose in 1–2 days. Increase intake of electrolyte-containing fluids as tolerated.
3	If unable to take oral glucocorticoids due to gastroenteritis (with vomiting or diarrhea) or acute trauma	Early administration of iv or im or sc Injection hydrocortisone 100 mg. To be repeated after 6–12 h until recovery. To go to hospital at the earliest after emergency injection hydrocortisone. Consult an endocrinologist or physician.
4	Significant emotional or mental stress (e.g.: Death of a close relative or writing board examination)	To add 10–20 mg of tablet hydrocortisone to daily replacement dose.
5	Exhaustive strenuous exercise	To intake 10 mg of tablet hydrocortisone 30–60 min before exercise.

AI- Adrenal Insufficiency, im- intramuscular, sc- subcutaneous, iv- intravenous. (Modified from Allolio *et al.*^[6])

in all given situations correctly. Almost 80% of patients did not correctly identify all symptoms of glucocorticoid under-replacement. In another study done by Bouziane T *et al.*^[12] among 55 patients with AI, an even larger percentage (74%) of patients had insufficient understanding of their disease.

In a patient with intolerance to oral medications due to vomiting or trauma, or undergoing surgery, or with symptoms of AI or AC, early parenteral (intravenous [iv], intramuscular [im], or subcutaneous [sc]) injection of 100 mg hydrocortisone is indicated [Table 4].^[4] This simple measure of self-injection of hydrocortisone in case of an emergency before contacting the treating endocrinologist or a general physician can be lifesaving in these individuals. Among our subjects, only 36.9% (34) were aware that injection hydrocortisone must be administered at times of intolerance to oral glucocorticoid medication. Of the 17 patients requiring hospitalization for AC, only 11.7% (2) had self-administered or received injection hydrocortisone during illness or before the procedure.

Previous studies have demonstrated that infection especially gastroenteritis is the most common precipitate for AC.^[13–15] Among our subjects, hospitalization for AC was seen in 18.5% (17) of the participants after initial diagnosis of AI, with infection being the most common precipitating cause of AC in 70.6% (12), followed by noncompliance to CRT in 17.6% (3).

Every patient must be provided with a steroid emergency card/steroid alert card to inform healthcare providers about the diagnosis and need for CRT and stress steroid dosing.^[4] While a majority of the partakers in our study (96.7%) were holders of steroid alert cards, 12% (11) were unaware that it must be always carried by them in person.

It has been shown in previous studies that, despite repeated verbal communication during treatment over several years and continuous follow up by trained endocrinologists, a significant proportion of patients (46%) were not adequately knowledgeable or skilled in self-management during physical stress.^[16] In an investigation of 338 patients with AI, only 51.9% of the questions on CRT were answered correctly.^[17] In another study, 43 (51.8%) of the 83 patients with AI who

had previously received education had insufficient knowledge about how to act during stressful situations.^[18]

In our study, the partakers who missed increasing doses of glucocorticoids during illness and those who failed to carry a steroid alert card were relatively older than those who did. This could reflect a need to develop, implement, and evaluate effective education strategies for older patients with AI. Further studies are required to confirm the effect of the age of participants on knowledge and practice in AI.

Our findings illustrate deficits in knowledge and self-management in patients with AI at follow up visits despite receiving prior education at least once. This nescience persisted across different literacy levels and duration since diagnosis of illness, reflective of a systematic issue in patient education. There is a need for continual education of patients with AI by the treating endocrinologist at every visit with reinforcement of knowledge about AI, CRT, and practical implementation of stress dosing of glucocorticoids during illness [Table 5]. Periodic training of patients and family members or caregivers on sc or im self-administration of injection hydrocortisone, with adaptation to specific needs like in the elderly, is necessary to achieve lasting proficiency in coping with stress situations in AI. Providing written instructions or printed pamphlets with suggested actions in special situations [Table 4] could improve self-assurance and patient care. Auxiliary tools like online videos, online patient awareness programs, and apps could help sustain patient's knowledge. The creation of patient support groups could further help in enhancing awareness and providing support for patients with AI and their family members.

Group education could be a helpful tool in improving self-care in patients with AI. In a longitudinal, prospective study, nine German endocrine centers established a standardized education program for patients with AI. During the 2-hour program, basic knowledge on AI was provided, all were equipped with emergency cards and sets and trained in self-injection of hydrocortisone. Patients from eight certified centers completed questionnaires before, immediately after, and 6–9 months

Table 5: Main points for education of patients with AI and their family members on self-management for AC prevention**Points to reinforce on self-management in patients with AI.**

Explain symptoms and signs of emergent AC like hypotension or giddiness, nausea, vomiting, loss of appetite, abdominal pain, fever, severe fatigue, somnolence, hypoglycemia, and hyponatremia or hyperkalemia.

Discuss situations requiring oral glucocorticoid dose adjustment and parenteral self-administration of hydrocortisone emergency injection.

Explain the rationale and the dose of glucocorticoid tablets in stressful situations.

To ensure a sufficient supply of glucocorticoid tablets accounting for probable sick days.

To ensure every patient has a hydrocortisone emergency injection kit (comprising a vial of hydrocortisone 100 mg injection, 2cc syringe and needle, and insulin syringe) for possible sick days and can self-administer subcutaneously or intramuscularly.

Reinforce the need to go to the hospital after an emergency hydrocortisone injection and in case of worsening condition of the patient during illness despite stress dosing of glucocorticoid.

To ensure frequent checks on the expiry date of both oral medication and hydrocortisone injection and to dispose of medications that have passed the expiry date.

To check every patient has a steroid emergency card and reinforce that it must be always carried by them.

To ensure every patient has a leaflet or card with information on the diagnosis of the patient and advice regarding the need for the injection of 100 mg hydrocortisone in case of illness to be shown to health care professionals for prompt care in emergencies/AC.

To reinforce the need to communicate about diagnosis of AI to any treating physician or surgeon, to alert the doctor to look at possible interaction with glucocorticoid tablets when initiating medications for other illnesses or comorbidities.

To provide the emergency contact number of the endocrinology team.

after training. After patient education significantly higher questionnaire score values were seen, implying effective knowledge transfer (baseline values: 17 ± 7.1 of a maximum score of 29; values after training: 23 ± 4.2 ; $P < 0.001$). This remained stable over 6–9 months demonstrating considerable benefits of a standardized group education in AI. Now, more than 70 centers certified by the German Endocrine Society regularly offer this form of education to patients with AI.^[19] There is a need to develop a standardized education program for effective group education in India.

As this is a questionnaire-based study there is the probability of self-report bias. We have not addressed the effect of factors like different modes of healthcare provider interaction, types of healthcare systems, or access to educational resources in our study. Our findings are despite every patient receiving education about AI and being taught stress dosing of glucocorticoid and self-administration of Injection hydrocortisone at least once after diagnosis at the endocrinology department in a single tertiary care hospital in India. This may not be reflective of knowledge and practice among other primary care or tertiary care centers. However, it is alarming to consider the nescience among patients and the resulting complications that could arise due to a lack of measures to educate patients with AI

at health care centers. Thus, going forward, there is a need for longitudinal studies to assess the impact of different factors on patient knowledge and practice and to develop, evaluate, and effectuate standardized educational interventions in AI.

CONCLUSION

This questionnaire-based study is probably the first of its kind done to assess knowledge and practice among patients with AI in India. Here we have shown that there continues to be a deficit in knowledge and self-management among individuals with AI. This demonstrates the need to reassess knowledge, educate, and reinforce good practices at every follow up visit to prevent AC and improve the quality of life in individuals with AI. Going forward, it is necessary to devise, assess and implement effective standardized educational interventions in AI.

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Author contributions

Dr. Ganapathi Bantwal, Dr. Vageesh Ayyar, and Dr. Belinda George conceptualized the idea. Dr. Sonali Appaiah, Dr. Aishwarrya Umeshchandara G, Dr. Deepa Kulkarni, and Dr. Vishwanath S conducted the study. Dr. Aishwarrya Umeshchandara G and Dr. Deepa Kulkarni compiled the data. Dr. Sonali Appaiah and Dr. Aishwarrya Umeshchandara G analyzed and interpreted the data and searched the literature. Dr. Sonali Appaiah wrote the first draft. All the authors edited the subsequent and final draft. All authors agreed mutually to submit for publication.

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Conflicts of interest

There are no conflicts of interest.

Data availability statement

The authors of this manuscript are willing to share the data supporting the results of this manuscript upon request.

REFERENCES

- Hahner S, Ross RJ, Arlt W, Bancos I, Burger-Stritt S, Torpy DJ, *et al.* Adrenal insufficiency. *Nat Rev Dis Primers* 2021;7:19.
- Husebye ES, Pearce SH, Krone NP, Kämpe O. Adrenal insufficiency. *Lancet* 2021;397:613-29.
- Rushworth RL, Torpy DJ, Falhammar H. Adrenal crisis. *N Engl J Med* 2019;381:852-61.
- Bornstein SR, Allolio B, Arlt W, Barthel A, Don-Wauchope A, Hammer GD, *et al.* Diagnosis and treatment of primary adrenal insufficiency: An Endocrine Society clinical practice guideline. *J Clin Endocrinol Metab* 2016;101:364–89.
- Arlt W; Society for Endocrinology Clinical Committee. Society For Endocrinology Endocrine Emergency Guidance: Emergency

- management of acute adrenal insufficiency (adrenal crisis) in adult patients. *Endocr Connect* 2016;5:G1-3.
6. Allolio B. Extensive expertise in endocrinology. Adrenal crisis. *Eur J Endocrinol* 2015;172:R115-24.
 7. Gidlöf S, Falhammar H, Thilén A, von Döbeln U, Ritzen M, Wedell A, *et al.* One hundred years of congenital adrenal hyperplasia in Sweden: A retrospective, population-based cohort study. *Lancet Diabetes Endocrinol* 2013;1:35-42.
 8. Torpy DJ, Bancos I, Husebye E. Adrenal insufficiency. In: Robertson RP, Giudice LC, Grossman AB, Hammer GD, Jensen MD, Kahaly GJ, *et al.*, editors. *DeGroot's Endocrinology: Basic Science and Clinical Practice*. 8th ed. Copyright © by Elsevier Inc; 2023. p. 1553-68.
 9. Chernow B, Alexander HR, Smallridge RC, Thompson WR, Cook D, Beardsley D, *et al.* Hormonal responses to graded surgical stress. *Arch Intern Med* 1987;147:1273-8.
 10. Sapolsky RM, Romero LM, Munck AU. How do glucocorticoids influence stress responses? Integrating permissive, suppressive, stimulatory, and preparative actions. *Endocr Rev* 2000;21:55-89.
 11. Kampmeyer D, Haas CS, Moenig H, Harbeck B. Self-management in adrenal insufficiency — towards a better understanding. *Endocr J* 2017;64:379-85.
 12. Bouziane T, Belmahi N, Salhi H, Ouahabi HE. Knowledge and attitude of patients with adrenal insufficiency. *Ann Afr Med* 2020;19:252-7.
 13. Hahner S, Loeffler M, Bleicken B, Drechsler C, Milovanovic D, Fassnacht M, *et al.* Epidemiology of adrenal crisis in chronic adrenal insufficiency: The need for new prevention strategies. *Eur J Endocrinol* 2010;162:597-602.
 14. Rushworth RL, Torpy DJ. A descriptive study of adrenal crises in adults with adrenal insufficiency: Increased risk with age and in those with bacterial infections. *BMC Endocr Disord* 2014;14:79.
 15. Hahner S, Spinnler C, Fassnacht M, Burger-Stritt S, Lang K, Milovanovic D, *et al.* High incidence of adrenal crisis in educated patients with chronic adrenal insufficiency: A prospective study. *J Clin Endocrinol Metab* 2015;100:407-16.
 16. Flemming TG, Kristensen LO. Quality of self-care in patients on replacement therapy with hydrocortisone. *J Intern Med* 1999; 246:497-501.
 17. Harsch IA, Schuller A, Hahn EG, Hensen J. Cortisone replacement therapy in endocrine disorders – quality of self-care. *J Eval Clin Pract* 2010;16:492-8.
 18. Van der Meij NTM, van Leeuwen RS, Vervoort SC, Zelissen PM. Self-management support in patients with adrenal insufficiency. *Clin Endocrinol* 2016;85:652-9.
 19. Burger-Stritt S, Eff A, Quinkler M, Kienitz T, Stamm B, Willenberg HS, *et al.* Standardised patient education in adrenal insufficiency: A prospective multi-centre evaluation. *Eur J Endocrinol* 2020;183:119-27.

QUESTIONNAIRE

Knowledge

1. Have you been explained about your diagnosis? Yes or No
2. Have you received any specific information regarding medication dose during illness? Yes or No
3. Hydrocortisone / prednisolone hormone tablet is important for survival. Yes or No
4. What are the symptoms of low levels of blood cortisol hormone (adrenal crisis)?
 - a. Nausea/vomiting b. loss of appetite c. tiredness/severe fatigue d. fever e. giddiness/low blood pressure f. abdominal pain g. Not aware.
5. In which situations should the dose of Glucocorticoid (hydrocortisone/prednisolone) be increased?
 - a. Mild Fever (<38°C) b. moderate fever (>38°C) c. vomiting d. loose stools/diarrhea e. surgery/procedure f. Not aware.
6. By how much should the dose of glucocorticoid be increased?
 - a. Need not increase b. increase by 2 times c. increase by 4 times d. increase by 1.5 times e. Not aware.
7. For how many days should the dose of glucocorticoid be increased?
 - a. 1 day b. 2 days c. 3 days d. 1 week e. duration of illness f. Not aware.
8. What should be done if there is vomiting?
 - a. Continue taking glucocorticoid tablets b. stop glucocorticoid tablet c. Take injection Hydrocortisone d. Not aware.
9. Should the dose of fludrocortisone be increased during an illness? Yes/No
(applicable in primary adrenal insufficiency)
10. Have you been taught to take injection hydrocortisone by yourself? Yes/No
11. Have you received a steroid alert card? Yes/No
12. Can you stop hydrocortisone/prednisolone without the advice of your doctor? Yes/No

Practice

13. Have you stopped treatment on your own? Yes/No
 14. Have you missed increasing the dose of medications during an illness? Yes/No
- Have you ever required hospitalization or medical care for symptoms of adrenal insufficiency after the initial diagnosis or have you undergone any medical procedures in the past? Yes/No
- If yes,
15. What was the precipitating event for hospitalization or for seeking medical care ? Respiratory infection/ gastrointestinal tract infection/ other febrile illness/ procedure / missed dose of medication
 16. If yes, did you receive extra dose of hydrocortisone prior to the procedure? Yes/No
 17. If yes, have you taken inj. hydrocortisone by yourself during the illness? Yes/No
 18. Do you carry a steroid alert card when travelling out of station? Yes/No