Knowledge and Attitude of Patients with Adrenal Insufficiency

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Abstract

Background: Adrenal insufficiency (AI) is a rare and a dangerous disease requiring a life-long glucocorticoid replacement therapy with dose adjustment in stressful situations which is linked to patient’s knowledge and understanding. The aim of this study was to explore AI patients understanding regarding their disease, risk factors of adrenal crisis, as well as their attitude in stressful situations.

Materials and Methods: We prospectively enrolled from October to January 2017, all patients with adrenal insufficiency (primary or secondary) treated and followed up in the Department of Endocrinology at University Hospital Center Hassan II of Fez. Patients were asked to fill out a questionnaire to assess their self-perceived subjective understanding to objectively evaluate their knowledge.

Results: A total of 55 AI patients participated in this study. Overall, 74% of patients had no sufficient understanding of their disease; more participants gave incorrect answers to how to act in different stressful situations. Eleven patients (20%) did not possess a “steroid warning card,” twenty-five patients (45%) had the injectable hydrocortisone (HC) set at home; 40% carried the HC required for the day with them. Globally, the patients self-perceived, subjective knowledge level was not good, a severe lack of knowledge had been identified concerning the knowledge of risk factors of AI.

Conclusion: The present study shows the urgent need to develop a structured and continuous education of patients with adrenal insufficiency to improve their self-management of the disease.

Keywords: Adrenal insufficiency, education, knowledge, self-management

Résumé

Introduction: L’insuffisance surrénalienne (IS) est une maladie rare et grave nécessitant une thérapie de remplacement à vie par des glucocorticoïdes avec ajustement des doses dans des situations stressantes. Le but de cette étude était d’explorer la compréhension des patients atteints d’insuffisance surrénalienne sur la pathologie, les facteurs de risque d’une crise aiguë surrénalienne et sur la gestion de leur traitement substitutive dans des situations stressantes.

Matériel et Méthodes: Nous avons recruté prospectivement d’Octobre à Janvier 2017, tous les patients souffrant d’insuffisance surrénalienne (primaire ou secondaire) traités et suivis au Département d’Endocrinologie du Centre Hospitalier Universitaire Hassan II de Fès. Les patients ont été invités à remplir un questionnaire pour évaluer leur compréhension subjective afin d’évaluer objectivement leurs connaissances.

Résultats: Un total de 55 patients ont participé à cette étude. Dans l’ensemble, 74% des patients n’avaient pas une compréhension suffisante de leur maladie, beaucoup plus de participants ont donné des réponses incorrectes sur la façon d’agir dans différentes situations stressantes. Onze patients (20%) ne possédaient pas de « carte d’addisonien » et uniquement vingt-cinq patients (45%) se disposaient de l’hydrocortisone injectable (HC) à la maison ; 40% uniquement emportaient avec eux la dose journalière d’hydrocortisone. Globalement, le niveau des connaissances subjectif perçu par les patients n’était pas bon, surtout concernant la connaissance des facteurs de risque de l’insuffisance surrénalienne.

Conclusion: Notre étude montre le besoin urgent de développer une éducation structurée et continue des patients souffrant d’insuffisance surrénalienne pour améliorer leurs autogestion de la maladie.

Mots-clés: Insuffisance surrénalienne, Education, Connaissances, Autogestion

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**INTRODUCTION**

Adrenal insufficiency (AI) is a chronic condition caused by the destruction of the adrenal glands (primary adrenal failure) or due to impairment of the hypothalamic-pituitary axis (secondary adrenal failure). Treatment usually requires life-long replacement therapy with glucocorticoids (GCs), which has to be adjusted in response to stressful events in healthy individuals to prevent an adrenal crisis. Compliance with the treatment is linked to adequate education and understanding of the disease as it has been shown in other chronic conditions such as diabetes.

Retrospective data indicate increased mortality in both primary and secondary AI. Therefore, a continuous education of patients and their families is necessary to prevent life-threatening emergencies.

A few studies investigated the knowledge of patients with adrenal insufficiency.

The aim of our study was to assess the present state of knowledge and skills of adrenal insufficiency patients to evaluate objectively their self-management capabilities.

**MATERIALS AND METHODS**

We conducted a descriptive prospective study in patients with primary or secondary adrenal insufficiency treated at the Department of Endocrinology, Diabetology, and Nutrition at University Hospital Center Hassan II in Fez.

Data were collected in 4 months from October to January 2017, a total of 55 patients were asked to fill out a questionnaire with various possible answers on the subject of AI. The questionnaire [Appendix 1] was developed from key themes in the literature and from the clinical researchers’ experience in the field. It concluded a general information section, school graduation, and occupational status; data on the duration and causes of AI, medication, additional health problems, and recent emergency situations necessitating parenteral GC treatment (severe illness and surgery).

Patients were further asked for the risk factors and symptoms of an emerging adrenal crisis as well as the instructions in GC therapy adjustment in milder diseases, stress, and the equipment with a “steroid warning card” or an emergency GC kit (supply of hydrocortisone [HC] vials), the instruction about utilization of the kit.

Each patient was interviewed only once, and all questionnaires were filled out and entered into Excel datasheet, and a descriptive analysis of the patient group was performed. Categorical variables are presented as numbers (percentages), and continuous variables are expressed as means.

**RESULTS**

**Respondents**

Of 55 patients asked, 16 were males and 39 females with a mean age of 49.5 years (age range 18–63 years) with a median duration of adrenal insufficiency of 10.5 years (range 2–21). Patients’ characteristics presented in Table 1 showed that 49 patients suffered from secondary adrenal insufficiency mostly due to long-term therapeutic corticosteroids, whereas only six patients had a primary AI related to an Addison disease. The average daily dose of HC was 20 mg (range 15–40 mg).

A minority (10%) of patients had professional tertiary education and were regular Internet users and had annual follow-ups.

**Subjective understanding and knowledge of the disease**

All the participants described their journey from the diagnosis announcement to the present.

The self-perceived knowledge of the definition of AI was rated as below:

- Twenty-six percent were not able to name correctly the adrenal deficiency
- Forty-eight percent had given an incorrect answer
- Twenty-six percent of patients had the correct knowledge of the definition of AI.

**Risk factors for the adrenal crisis**

- Three of the participants had previous hospitalizations for an adrenal crisis (primary adrenal crisis leading to diagnosis was not count). All had an Addison disease; two of them were able to identify signs and symptoms of adrenal crisis before diagnosis due to the severity of symptoms experienced in the first primary crisis
- The reason for the occurrence of alternating current (AC) was interrupting the treatment in two cases and gastroenteritis in the third case.
- When asked about their knowledge of reasons leading to the adrenal crisis:
- Ninety percent of responding knew that it can occur if stopping, forgetting substitution treatment, 40%

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**Table 1: Patients demographics**

| Patients demographics | n   |
|-----------------------|-----|
| Gender               |     |
| Female               | 39  (71) |
| Male                 | 16  (29) |
| Age, median (range)  | 49.5 (18-63) |
| BMI (kg/m²)          | 27±4.8 |
| Cause of AI, n       |     |
| Primary AI           | 6   |
| Secondary AI         | 49  |
| Duration of AI (years), median (average) | 10.5 (2-21) |
| Hydrocortisone dose (mg), median (range) | 20 (15-40) |
| AC since primary diagnosis, n | 3  |
| Educational background, n |     |
| Analphabet           | 23  |
| Primary education    | 18  |
| Secondary education  | 8   |
| Tertiary education   | 6   |

AC=Adrenal crisis, AI=Adrenal insufficiency, BMI=Body mass index
ignored that health conditions such as gastroenteritis, fever, infection, fracture, cardiovascular accident, surgery or invasive examination bronchial or digestive can lead to AC if lack of HC dose adjustments, 60% of participants were aware that the use of drugs reducing the effectiveness of the treatment of adrenal insufficiency can lead to an AC, and most of them showed their treatment if consulting for another medical health

• None of our patients had the knowledge that a very strong emotion can lead to adrenal crisis.

Evaluation of self-management knowledge and preventive measures

To identify AI patient’s competence in self-managing their disease: all participants were interviewed regarding their behaviors with GCs dose adjustments in the most severe hypothetical conditions: The results summarized in Tables 2 and 3 showed severe knowledge deficits, less remarkable in patients with a high educational background

• Interviewees were also asked about the possessing of an emergency AI card and a HC emergency kit; the majority of our AI patients (n = 52; 80%) were holder of an emergency AI card. About 45% (n = 24) possessed an emergency kit, but only 14 patients knew the instructions of using it; ten patients even claimed not to have received any instructions for correct using.

• Concerning other preventive measures: 92% of patients had the knowledge that fasting is not allowed in patients with AI; 48% knew that they should not restrict salt intake.

Evaluation of the GC therapy compliance

• Ninety percent of patients declared that they never interrupt the treatment at least in the past year; 40% noticed that they carry the HC required for the day with them

• Nonobservant patients referred their noncompliance to the lack of financial resources (in 6%), others (4%) claimed that they did not always receive support and clear education by the health care professionals

• Symptoms of over- or under-replacement therapy were known by a minority of patients (n = 20); weight gain and asthenia were the major symptoms known as signs of over- and-under replacements, respectively; only six patients were able to name hypertension and hyperglycemia as symptoms of over-replacement.

Discussion

AI is known as a rare and mortal disease in the case of acute AC. The lack of specificity of the signs and the lack of knowledge of this medical emergency leads to a delayed start of treatment that may precipitate a fatal outcome.

Data on the incidence, risk factors, and outcomes of AC are limited. Its approximately 6–7.5/100 patient-years.[12] It was accounted for 36 of the 507 deaths (7%) in a previous Swedish Registry study[4] in patients with Addison’s disease and 59 of the 106 unexpected deaths (56%) in a US cohort of 6107 patients treated with growth hormone.[6]

Accordingly, the international and French consensus of the management of primary adrenal insufficiency[7] had recommended that each AI patient and his family should be trained to identify symptoms of an emerging adrenal crisis and instructed in GC therapy adjustment, and the use of emergency injection (im or sc) of HC. A “Steroid warning card” that should be carried at all times to alert attending physicians to the need of dose adjustments, in the case of physical stress beside other programs that could respond to patients’ needs concerning HC adjustment to avoid over- or under-replacement.

The level of knowledge and understanding of AI was assessed in previous studies.[6-12] It was good in only 15 of the 25 patients in an English study[13] and in 5% of the 84 patients in a Danish study[14] in the 1990s, it was disappointing in our study too, only 28% of correct answers when asked about the definition of AI. Hahner et al.[3] also concluded that only a few number of risk factors of AC were targeted in the education, and new concepts of prevention are needed. So as expected, patients were not aware of the major risk situations of AC, and about half of the patients could not recall ever

| Table 2: Percentage of correct answers with respect to hydrocortisone adjustments |
|---------------------------------|-------------------|
| Stressful events requiring hydrocortisone adjustments | Percentage |
| A cold                           | 34               |
| Fever                           | 46               |
| Diarrhea                        | 12               |
| Vomiting                        | 20               |
| Surgery                         | 48               |
| Acute several illness           | 56               |
| Psychological stress            | 0                |
| Dental treatment; headache      | 2                |

| Table 3: Characteristics of patients with good knowledge of adrenal insufficiency |
|---------------------------------|-------------------|
| Patients                        | n (14)            |
| Age (years), median             | 31                |
| Gender, n (%)                   |                   |
| Female                          | 10 (71)           |
| Male                            | 4 (29)            |
| Cause of AI, n                  |                   |
| Primary AI                      | 1                 |
| Secondary AI                    | 13                |
| Duration of AI (years), median (average) | 11 (2-21) |
| Educational background, n       |                   |
| Analphabet                      | 0                 |
| Primary education               | 0                 |
| Secondary education             | 0                 |
| Tertiary education              | 8                 |

AI=Adrenal insufficiency
being advised to adjust their HC doses during acute illness or stressful events. This is reflected in the low percentage of appropriate interviewees responses when faced with a hypothetical illness or vomiting.

Twenty percent of patients were not holder of a “steroid warning card” which is similar to other studies. While forty percent only present the card at each visit or consultation for an undercurrent illness.

Few patients had injectable HC sit as its reported in similar previous studies which could be explained by the “corticophobia,” as most of the patients expressed the lack of confidence in their knowledge, the fear of doing wrong, the belief in the omnipotence of the medical word.

More worryingly, previous data reported that even well-educated AI patients had made poor decisions in some stressful situations. Hence, it is important to constantly re-evaluate patients’ understanding and assess their reaction to illness.

The main source of information for adrenal insufficiency patients is health professionals. This may be due to the characteristics and the age of participants as they are middle aged (Mean: 49.5 years in our study) or olds, their educational background as the majority are analphabets or had only received a primary education. This situation may change in the future as younger patients are more familiar with new modern technologies and have more access to Internet. In a recently published study the majority of adrenal insufficiency patients (90.0%) was satisfied with the information delivered by their health providers regarding their pathology. Moreover, Kampmeyer et al. showed in their study that a majority of caregivers of different hospitals and specialties had given a controversies answers regarding GC replacement in various hypothetical situations, this highlights the necessity of an improved correct education and information of health professionals to improve the managing of AI emergencies as endocrinologists are not often consulted when AI patients are admitted for other health problems.

Concerning adherence to the treatment; a recent study referred noncompliance to the lack of information provided on the therapeutic approach, which is reported in 16% of nonobservers in our study, or due to the fear of sides effects such as hyperglycemia and weight gain.

Our study underscores the severe lack of knowledge of adrenal insufficiency patients and the urgent need of additional efforts to educate patients, their families, and caregivers regarding this disease using a structured and quality-controlled approach.

**Conclusion**

Continuous education of patients with adrenal insufficiency is an extreme necessity to reduce the incidence of adrenal crisis. As caregivers are the main source of education, they should give more efforts to full patients’ knowledge gaps.

Some suggestions may help to improve this such as media, printed information, and education group meetings that also proved their efficacy in such chronic diseases such as diabetes. A motivational interviewing of patients is also needed to help them develop motivation to self-manage their disease.

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**Conflicts of interest**

There are no conflicts of interest.

**References**

1. Arlt W. Adrenal insufficiency. Clin Med (Lond) 2008;8:211-5.
2. White K, Arlt W. Adrenal crisis in treated Addison’s disease: A predictable but under-managed event. Eur J Endocrinol 2010;162:115-20.
3. Hahner S, Loeffler M, Bleibek B, Dreichler 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.
4. Berghorsdottir R, Leonnsson-Zachrisson M, Ödén A, Johannsson G. Premature mortality in patients with Addison’s disease: A population-based study. J Clin Endocrinol Metab 2006;91:4849-53.
5. Burman P, Mattsson AF, Johannsson G, Höybye C, Holmer H, Dalhqvist P, et al. Deaths among adult patients with hypopituitarism: Hypocortisolism during acute stress, and de novo malignant brain tumors contribute to an increased mortality. J Clin Endocrinol Metab 2013;98:1466-75.
6. Mills JL, Schonberger LB, Wysowski DK, Brown P, Durako SJ, Cox C, et al. Long-term mortality in the United States cohort of pituitary-derived growth hormone recipients. J Pediatr 2004;144:430-6.
7. Guignat L. Therapeutic patient education in adrenal insufficiency. Ann Endocrinol (Paris) 2018;79:167-73.
8. Kampmeyer D, Haas CS, Moeing H, Harbeck B. Self-management in adrenal insufficiency – Towards a better understanding. Endocr J 2017;64:379-85.
9. van Eck JP, Gobbens RJ, Beukers J, Geilvoet W, van der Lely AJ, Neggers SJ. Much to be desired in self-management of patients with adrenal insufficiency. Int J Nurs Pract 2016;22:61-9.
10. 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.
11. Chapman SC, Lahana SB, Carroll P, Horne R. Glucocorticoid therapy for adrenal insufficiency: Nonadherence, concerns and dissatisfaction with information. Clin Endocrinol (Oxf) 2016;84:664-71.
12. Touraine P, Chenuc G, Colin C. Self-perceived health status of patients with adrenal insufficiency receiving glucocorticoid replacement therapy – French data from a worldwide patient survey. Ann Endocrinol (Paris) 2015;76:9-12.
13. Braatvedt GD, Newrick PG, Corrall RJ. Patients’ self-administration of hydrocortisone. BMJ 1990;301:1312.
14. Flemming TG, Kristensen LO. Quality of self-care in patients on replacement therapy with hydrocortisone. J Intern Med 1999;246:497-501.
15. Peacey SR, Pope RM, Naik KS, Hardern RD, Page MD, Belchetz PE. Corticosteroid therapy and intercurrent illness: The need for continuing patient education. Postgrad Med J 1993;69:282-4.
16. Chapman SCE, LLahana S, Carroll P, Horne R. Glucocorticoid therapy for adrenal insufficiency: Nonadherence, concerns and dissatisfaction with information. Clin Endocrinol (Oxf) 2016;84:664-71.
APPENDIX

Appendix 1: Questionnaire of evaluation of the knowledge in the patients with primary or secondary adrenal insufficiency

Questionnaire of evaluation of the knowledge in the patients with primary or secondary adrenal insufficiency

A. General:
- Age:
- Gender: Female: □ Male: □
- Educational background:
  - Analphabet: □ -Primary education: □
  -Secondary education: □ -Tertiary education: □
  - Access to internet: Yes: □ No: □

B-Etiology of adrenal insufficiency:
-Primary AI:
  - Autoimmune diseases: □
  - Tuberculosis: □
  - Adrenal metastases: □
  - HIV viral diseases: □
  - Vascular diseases: □
  - Bilateral adrenalectomy: □
  - Drug intake: □
  - Congenital adrenal hyperplasia: □
-Secondary AI:
  - Long-term corticotherapy: □ → pathology: -
  - IS in the context of ante-pituitary insufficiency: □
  + Tumor causes (adenoma.): □
  + Infectious causes (TB.): □
  + Vascular causes (Nd de Sheehan.): □
  + Infiltrative causes (hypophysitis, sarcoidosis.): □
  + Empty turcic stool: □
  + Iatrogen: radiotherapy; Surgery

C-History of Adrenal crisis:
If yes =>Number: Frequency: Risk Factors:

D- Questions which assessed knowledge about AI and AC:
1-What is adrenal insufficiency?
A: correct answer
B: Insufficient answer
C: No answer
2-How long have you had adrenal insufficiency?
3- Diagnosed when and how? Medication?
4-Have you ever had an Addisonian crisis?
5- Under what circumstances can acute adrenal insufficiency occur?
   - Stopping substitution treatment (forgetting, neglect, lack of prescription, to check if you are really “dependent” on treatment.); □
   - Gastroenteritis, fever, infection, fracture, cardiovascular accident, surgery or invasive examination (bronchial or digestive fibroscopy.); □
   - Very strong emotion (happy or unhappy) □
   - Pregnancy □
   - Hyperthyroidism □
   - Use of drugs reducing the effectiveness of the treatment of adrenal insufficiency: □
E-Questions assessing the knowledge about managing stressful events in healthy subjects:
1- Have you been advised what to do with your medication in times of stress/illness?
2- In which situations you have to increase the hydrocortisone dose?
   - A cold □
   - A Fever □
   - An infection □
   - Diarrhea □
   - Vomiting □
   - Psychological distress, e.g. car accident without injury, bereavement □
   - Surgery □
   - Dental treatment
3- Do you knew that fasting is forbidden in patients with AI?
4- Do you have an emergency hydrocortisone injection kit?
   - Do you knew instruction of how to use it?
   - Have you ever needed to use this? If not, is this something you would consider having?
5- Do you have a steroid worming Card?
F- Questions assessing the compliance:
   - Drug compliance □
   - Compliance with associated measures □
   - Compliance with follow-up □
   - If non-compliance:
     => The responsible factors: