

Survey for Medical Community on Adrenal Insufficiency

The NADF with support from Opinion Health, a healthcare research agency based in London, UK, conducted a National Survey on adrenal Insufficiency (AI). This was a short, on-line survey for healthcare professionals (HCP). It was designed to better understand current diagnosis and management of AI, especially in patients with Addison's disease. The link to the survey was posted on the NADF website; additionally, it was distributed to medical professionals by NADF members and during the Endocrine Society Annual meeting. One hundred respondents completed the survey, including 19 endocrinologists, 5 Internists, 7 general practitioners/family doctors, 13 nurse practitioners, 6 pharmacists, and others in the medical community, including dentists and nurses.

Research results

Summary

The results of the research survey indicate that:

- On a scale 1 to 10, where 1 is *Not knowledgeable at all* and 10 is *Very knowledgeable*, medical professionals assess their knowledge of adrenal diseases at 6.7 (relatively good), with endocrinologists estimating it at 7.8 (good);
- The amount and quality of information available on Addison's disease is assessed as average by medical professionals (scoring 5.6 on a scale of 1 to 10, where 1 is *Extremely dissatisfied* and 10 is *Extremely satisfied*);
- Addison's disease has a definite impact on life quality for patients (scoring 8.0 overall and 6.8 by endocrinologists on a scale 1 to 10 when 1 is *Not significant* and 10 *Extremely significant*).
- All doctors counsel their patients on medication and treatment, however guidance on management of adrenal crises and life style (e.g., diet, exercise) is lacking. Parents of children with Addison's disease receive minimal counselling.
- Based on received comments, we need better treatment, more education and awareness, and further research.

Main findings - discussion

Healthcare professionals estimate that they have a relatively good knowledge of adrenal diseases, although GPs, nurses and pharmacists report just fair knowledge and specialists admit that their knowledge is not at a top level. Their awareness about Addison's disease, adrenal Insufficiency and Cushing's syndrome is high, while Congenital Adrenal Hyperplasia and Hyperaldosteronism are not so well known, especially by GPs and nurses.

As expected, only endocrinologists and internists reported that they have experience treating Addison's disease, and some of them refer their patients to other peers. Endocrinologists and pharmacists are the only specialties directly involved in the day-to-day treatment and management of patients with Addison's disease. The other specialties are important in early diagnosis of the disease and early referral of patients to specialists.

In that context, it is important to examine how confident healthcare Professionals feel about their knowledge on the specific disease area. Internists and pharmacists assess their knowledge of Addison's disease as good. GPs and nurses as average. It is significant though, that 42% of endocrinologists assessed themselves with a score of 8 or less in a 10 points scale, indicating lack of thorough understanding of the disease.

Thus, when we investigated the awareness about symptoms, causes and treatment of Addison's disease, we had poor outcomes. First, we provided a list of 20 symptoms associated with Addison's disease, asking which of them would raise suspicions that a patient has Addison's disease. Even the most classical symptoms like "hyperpigmentation", "chronic exhaustion", "orthostatic hypotension", and "craving for salty foods" were not recognized by all physicians including endocrinologists. 19% of respondents, including 21% of endocrinologists did not associate hyperpigmentation with Addison's disease. 12% overall and 10% of endocrinologists did not associate chronic exhaustion with Addison's disease. Orthostatic hypotension was not recognized by 24% of respondents, including 11% endocrinologists. Finally, craving for salty food was not recognized by 25% respondents and 16% of endocrinologists.

The same image has been captured asking about the disease causes. Respondents could choose up to six options of Addison's disease causes or write in additional causes under the "other" category. "Autoimmune conditions" is generally perceived as the main cause. Most endocrinologists listed other possible reasons as "surgical removal of both adrenal glands", "tuberculosis or other infection", "adrenal haemorrhage". It was surprising to see that "pituitary adrenal insufficiency" and "Congenital Adrenal Hyperplasia" were also marked by 10% and 58 % respectively of endocrinologists. Addison's disease is a primary adrenal insufficiency and is not caused by either "pituitary adrenal insufficiency" or "Congenital Adrenal Hyperplasia".

As expected, mainly hydrocortisone and, in smaller percentages, cortisone-based regimens (cortisone acetate, fludrocortisone, prednisone, dexamethasone) are recognised by all specialties as treatments for Addison's disease. It is interesting to note that most HCPs also listed DHEA as one of treatment medications for Addison's disease. In line with the afore mentioned, Hydrocortisone is perceived by 80% of participants to be the most used medication, with fludrocortisone as the second option (70%). Discussing about medications, a significant unmet need for an effective treatment for Addison's disease was recorded in this survey, as all specialties stated that they are not satisfied with currently available treatments. Satisfaction by current treatments concentrated an average score of 5.6 in a 10-point scale.

Coming to the investigation of knowledge about adrenal crisis, we recorded a gap between specialists and non-specialists. A characteristic indication that most GPs are not fully knowledgeable about Addison's disease is the statistically significant difference in recognition of gastrointestinal illness as a frequent cause of adrenal crisis between endocrinologists (89.5% - 1st mentioned cause) and GPs (28.6% one of the least mentioned causes). All specialties recognize that a basic cause of adrenal crisis is the cessation of long-term corticosteroid treatment without tapering, but, once again, only endocrinologists consider bacterial infection as a serious cause of crises (84.2% vs 28.6% of GPs).

Nurses are the health care professionals who are less aware about stress dosing with steroids (23% of them are not aware of stress dosing with steroids) and 28.6% of GPs do not know or are not sure about the appropriate stress dose medication. On the other hand, 90% of endocrinologists, 60% of internists and 57% of GPs stated that the appropriate stress dose medication is 100 mg hydrocortisone I.V. until oral medication is tolerated. Only 30% of endocrinologists and even fewer internists noted that 100 mg hydrocortisone intramuscularly in a buttock or upper thigh is also an appropriate treatment during emergencies. Also, most HCPs (including 100% endocrinologists and

100% internists) give a stress dose of steroids during surgery to patients on chronic steroids. In accordance to this, the most mentioned medical procedure during which an HCP would administer a stress dose of corticosteroids is surgery with general anaesthesia (92% of respondents) followed by giving birth (63%). All endocrinologists would administer stress dose of hydrocortisone for a surgery with general anaesthesia. Only 30% of endocrinologists would administer stress dose of hydrocortisone for other procedures like colonoscopy, cataract, tooth extraction, or surgery with local anaesthesia.

On a relative topic, we found out that only 63% of the HCPs surveyed are aware of any procedure taken to treat adrenal insufficient patient during a gastrointestinal illness. The professional who appear to be less aware of this is the internist (60%) followed by GP and nurse (43% and 38.5% respectively). A really worrying finding is that one endocrinologist out of three is not aware of any procedure taken to treat an adrenal insufficient patient during a gastrointestinal illness.

Following, we asked HCPs to assess the impact of Addison's disease on patients' quality of life.

The mean rate for all respondents is 8 (very significant impact). Endocrinologists though, tend to rate the impact of Addison's disease at a lower level (6.8 on a scale from 1 to 10 with 1 *Not significant* and 10 *Extremely significant*). Regarding the improvement, the treatment offers, all respondents (on average) rated the impact of current treatment and management on Addison's patients' quality of life with a 7.6 (where 1 *No improvement at all* and 10 *Very significant improvement*). For endocrinologists, the impact factor is 7.3. We can conclude, that most healthcare professionals believe that Addison's disease has a very negative impact on the quality of patients' lives and treatment offers a good improvement.

We can see that an informative campaign is needed. Thus, we investigated the HCPs' favourite communication channels. The most used informational resources used are websites on Endocrinology (85%) followed by journals and publications (78%) and pharmaceutical company's websites (48%). It is interesting to note that 48% of respondents including 52% of endocrinologists seek information from colleagues.

Nevertheless, when comes to assessment of amount and quality of available information about Addison's disease HCPs are not satisfied.

The average level of satisfaction for all respondents concerning the amount of information is 5.6 (out of 10). Nurse practitioners and general practitioners/family doctors and endocrinologists are those professionals who are less satisfied, with a rate which is 5, 5.4 and 6.1 respectively.

Also, the average rate of the satisfaction from the quality of information is 5.9. Nurse practitioners and general practitioner/family doctors and endocrinologists are less satisfied (rate 5 and 6 respectively).

Only 75% of respondents provide information to patients diagnosed with Addison's disease. endocrinologists (89% of respondents) and internists (100%) are the HCPs who are more willing to provide information. Types of Information provided more frequently are those regarding crisis management (86%), medication and treatment (85%), travelling away from home (66%), and exercise (50%).

A deep need for improvement to the management of Addison's disease was recorded when HCPs were asked what they believe that would be the biggest improvement. There were over 70 comments to this question. Most (36) stated that better treatment and new medications would have the biggest impact on management of Addison's disease; 27 wished for more education and more awareness, 14 comments were in support of more research.

Conclusion

Although most healthcare professionals are aware of Addison's disease and believe that it has a significant impact on the quality of patients' lives, the majority of them are not well informed and knowledgeable about symptoms, causes and treatment and don't have experience and confidence in treating such patients. The level of knowledge about the treatment of an adrenal crisis is not satisfying at all and generally, there is a need for more information and of higher quality. The biggest improvement would be a new medication, but – until then- more education and increased awareness is the recommendation by HCPs. Obviously, a need for an informative campaign and continuous medical education courses, is a main conclusion of the research.

Summary of results to specific questions

Q1: On a scale of 1 to 10, how would you rate your knowledge of adrenal diseases?

HCP estimate that they have a relatively good knowledge of adrenal diseases (mean score 6.7). Fair knowledge reported GPs (mean score 5.0), nurses (6.2), pharmacists (6.5), good knowledge internists (7.4), and endocrinologists (7.8). Yet, it is significant that the score of specialists is not as high as it could be.

Q2: Which of the following adrenal diseases are you aware of?

Addison's disease (97%), adrenal Insufficiency (92%) and Cushing's syndrome (84%) concentrate higher awareness scores, while Congenital Adrenal Hyperplasia (53%) and Hyperaldosteronism (54%) are not so well known, especially by GPs and nurses.

Q3: Do you have experience treating or managing Addison's disease?

As expected, only endocrinologists and internists reported that they have experience treating Addison's disease (replied YES 90% and 100% respectively), while most GPs (57%) replied NO

Q4: Do you refer any of your patients with Addison's disease to another specialty?

Not every physician answered this question, making results difficult to interpret. It is worth noting that close to 30% of endocrinologists responded "yes".

Q5: Are you directly involved in the day-to-day treatment and management of patients with Addison's disease?

All (100%) endocrinologists and pharmacists are directly involved in the day-to-day treatment and management of patients with Addison's disease. A lot of physicians of other specialties stated that they are not involved.

Q6: On a scale of 1 to 10, how would you rate your knowledge of Addison's disease?

Internists and pharmacists assess their knowledge of Addison's disease as good (8) and (7.3) respectively. The GPs (5.7) and nurses (6.5) scores were lower. It is disappointing that 42% of

endocrinologists entered a score of 8 or less, indicating lack of thorough understanding of the disease.

Q7: Which of the following symptoms would cause you to suspect a patient has Addison's disease?

The list included 20 symptoms which are associated with Addison's disease. Even the most classical symptoms like "hyperpigmentation", "chronic exhaustion", "orthostatic hypotension", and "craving for salty foods" were not recognized by all physicians including endocrinologists. 19% of respondents, including 21% of endocrinologists did not associate hyperpigmentation with Addison's disease. 12% overall and 10% of endocrinologists did not associate chronic exhaustion with Addison's disease. Orthostatic hypotension was not recognized by 24% of respondents, including 11% endocrinologists. Finally, craving for salty food was not recognized by 25% respondents and 16% of endocrinologists.

Q8: As far as you are aware, which of the following could be the cause of primary Addison's disease?

The respondents could choose up to six options of Addison's disease's causes or write in additional causes under the "other" category. "Autoimmune conditions" is generally perceived as the main cause of Addison's disease. Most endocrinologists listed other possible reasons as "surgical removal of both adrenal glands", "tuberculosis or other infection", "adrenal haemorrhage". It was surprising to see that "pituitary adrenal insufficiency" and "Congenital Adrenal Hyperplasia" were also marked by 10% and 58 % respectively of endocrinologists. Addison's disease is a primary adrenal insufficiency and is not caused by either "pituitary adrenal insufficiency" or "Congenital Adrenal Hyperplasia".

Q9: As far as you are aware, which of the following medications are used for the treatment of Addison's disease?

As expected, mainly hydrocortisone and, in smaller percentages, cortisone-based regimens (cortisone acetate, fludrocortisone, prednisone, dexamethasone) are recognized by all specialties as treatments for Addison's disease. It is interesting to note that 52% of endocrinologists, 80% of internists, 43% of GPs, 38% of nurse practitioners, and 83% of pharmacists also listed DHEA as one of treatment medications for Addison's disease.

Q10: As far as you are aware, which of the following medications are most frequently used for the treatment of Addison's disease?

The majority (81%) of all health care professionals are aware that hydrocortisone is the most used medication, with fludrocortisone as the second option (70%).

Q11: On a scale of 1-10, how satisfied are you with currently available medications for treating Addison's disease?

A significant unmet need for an effective treatment for Addison's disease was recorded in this survey, as all specialties are not satisfied with currently available treatments, which concentrated an average score of 5.6 in a 10-point scale.

Q12: Which of the following are often causes of adrenal crisis?

Another indication that most GPs are not fully knowledgeable about Addison's disease is the statistically significant difference in recognition of gastrointestinal illness as a frequent cause of adrenal crisis between endocrinologists (89.5% - 1st mentioned cause) and GPs (28.6% one of the least mentioned causes). All specialties recognize that a basic cause is the cessation of long-term

corticosteroid treatment without tapering, but, once again, only endocrinologists consider bacterial infection as a serious cause of crises (84.2% vs 28.6% of GPs)

Q13: Are you aware of stress dosing with steroids?

It emerged that the health care professionals who are less aware about stress dosing with steroids are nurses (23% of them are not aware of stress dosing with steroids) followed by GPs (14.3%).

Q14: During an adrenal crisis, what is the appropriate stress dose medication?

28.6% of GPs do not know or are not sure about the appropriate stress dose medication. This group is followed by nurse practitioners and internists (respectively 23% and 20%). 90% of endocrinologists, 60% of internists and 57% of GPs stated that the appropriate stress dose medication is 100 mg hydrocortisone I.V. until oral medication is tolerated. Only 30% of endocrinologists and even fewer internists noted that 100 mg hydrocortisone intramuscularly in a buttock or upper thigh is also an appropriate treatment during emergencies.

Q15: Do you give a stress dose of steroids during surgery to patients on chronic steroids?

Most HCPs (including 100% endocrinologists and 100% internists) give a stress dose of steroids during surgery to patients on chronic steroids.

Q17: For which of the following medical procedures would you administer stress dose corticosteroids?

The most mentioned medical procedure during which an HCP would administer a stress dose of corticosteroids is surgery with general anaesthesia (92% of respondents) followed by giving birth (63%). All endocrinologists would administer stress dose of hydrocortisone for a surgery with general anaesthesia. Only 30% of endocrinologists would administer stress dose of hydrocortisone for other procedures like colonoscopy, cataract, tooth extraction, or surgery with local anaesthesia.

Q18: Are you aware of any procedure taken to treat an adrenal insufficient patient during a gastrointestinal illness?

Only 63% of the HCPs surveyed are aware of any procedure taken to treat adrenal insufficient patient during a gastrointestinal illness. The professional who appear to be less aware of this is the internist (60%) followed by GPs and nurse practitioners (with respectively 43% and 38.5%).

Tragically, one endocrinologist out of three is not aware of any procedure taken to treat an adrenal insufficient patient during a gastrointestinal illness.

Q19: On a scale of 1-10, how would you rate the impact that Addison's disease has on patients' quality of life?

The mean rate for all respondents is 8. Endocrinologists are those professionals who tend to rate the impact of Addison's disease at lower value (6.8 on a scale from 1 to 10 with 1 *Not significant* and 10 *Extremely significant*).

Q20: On a scale of 1-10, how would you describe the impact that current treatment and management has on Addison's patients' life quality?

On average, all respondents rated the impact of current treatment and management on Addison's patients' quality of life with a 7.6 where 1 *No improvement at all* and 10 *Very significant improvement*. For endocrinologists, the impact factor is 7.3.

Q21: Which of the following informational resources would you use to look for information on Addison's disease?

The most used informational resources used are websites on Endocrinology (85%) followed by journals and publications (78%) and pharmaceutical company's websites (48%). It is interesting to note that 48% of respondents including 52% of endocrinologists seek information from colleagues.

Q22: On a scale of 1-10, how satisfied are you with the amount of information available on Addison's disease?

The average level of satisfaction for all respondents is 5.6. Nurse practitioners and general practitioners/family doctors and endocrinologists are those professionals who are less satisfied about the amount of information available, with a rate which is 5, 5.4 and 6.1 respectively.

Q23: On a scale of 1-10, how satisfied are you with the quality of information available on Addison's disease?

The average level of satisfaction for all respondents is 5.9. nurse practitioners and general practitioner/family doctors and endocrinologists are those professionals who are less satisfied with the amount of information available, with a rate which is 5 and 6 respectively.

Q24: Do you provide information to patients diagnosed with Addison's disease?

Only 75% of respondents provide information to patients diagnosed with Addison's disease. endocrinologists (89% of respondents) and internists (100%) are the HCPs who are more willing to provide information.

Q25: Which of the following types of information do you provide to patients diagnosed with Addison's disease?

Types of Information provided more frequently are those regarding crisis management (86%), medication and treatment (85%), travelling away from home (66%), and exercise (50%).

Q26: In your opinion, what would be the biggest improvement that could be made to the management of Addison's disease?

There were over 70 comments to this question. Most (36) stated that better treatment and new medications would have the biggest impact on management of Addison's disease; 27 wished for more education and more awareness, 14 comments were in support of more research.