

Editorial: Diabetes Insipidus to be retired happily in history books

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Abbreviation: Arginine vasopressin deficiency (AVP-D), Arginine vasopressin resistance (AVP-R), Diabetes Insipidus (DI), Antidiuretic hormone (ADH).

In 1794, Johann Peter Frank coined the term “diabetes insipidus” to distinguish patients with this condition from those who had diabetes mellitus. A collaborative team of professionals from various international endocrinology and pediatric organizations is now recommending a change in nomenclature. They suggest that “diabetes insipidus” be replaced with “arginine vasopressin deficiency (AVP-D)” for cases of central origin, while proposing the term “arginine vasopressin resistance (AVP-R)” for nephrogenic cases (1)

In a study published in The Lancet, it was reported that over 1,000 patients indicated that 80% of them had their condition mistakenly identified as Diabetes Mellitus, which resulted in confusion and improper management. Furthermore, 85% expressed a desire for a change in the condition's name. There have been notable instances where patients suffered fatal outcomes due to dehydration because they did not receive desmopressin or fluids, as healthcare providers misdiagnosed them with Diabetes Mellitus. This situation is particularly tragic because it was preventable with appropriate treatment. A heartbreaking and avoidable death highlight the issues associated with the term “Diabetes Insipidus (DI) . (2)

In 2009, a 22-year-old man was admitted to a teaching hospital in London for an elective hip replacement. Although he was generally healthy, he required complete pituitary hormone replacement therapy, including desmopressin, due to panhypopituitarism following treatment for a suprasellar germinoma the previous year. His treatment for the germinoma involved high-dose glucocorticoids, which led to avascular necrosis of his hip. Prior to admission, it was recommended that the hospital’s endocrine team be notified of his case. Upon his arrival at the orthopedic ward, the surgery on the following day proceeded without complications. However, after returning to the ward, he exhibited confusion that increased significantly by the next day, presenting challenges for the nursing staff. At this point, he contacted the police via telephone, expressing distress about being extremely thirsty and not receiving any fluids. When law enforcement arrived at the ward, they were reassured by the staff that he is fine. Blood tests revealed normal glucose levels but a serum sodium concentration of 149 mmol/L. Shortly after 09:00 hours the following morning, the patient suffered a fatal cardiac arrest with a recorded serum sodium level of 169 mmol/L. This story highlighted the failure to inform the endocrine team on admission. It concluded that neither the doctors, nor nurses, nor pharmacists on the ward understood the complexity of the patient's medical condition. No desmopressin had been administered to the patient for 48 hours since his admission. The case summarized that the death was due to “dehydration contributed to by neglect. Some Suggestions arose after that to change the name include using the term “Pituitary Insipidus” for Cranial DI and “Renal Insipidus” for nephrogenic DI. (3).

We aspire for endocrinologists globally to adopt the newly established term AVP-deficiency to enhance the treatment of individuals affected by this condition. When considering fatalities due to dehydration, one typically thinks this happens in one of the developing nations where people struggle to get access to water. In fact, this tragedy has occurred within NHS hospitals. This Tragic death of that young man in London resulted from a "series of individual failures (4)

The Clinical Neuroendocrinology research team, headed by Mirjam Christ-Crain at the University Hospital Basel. This team has conducted a large survey about treatment-related adverse effects for diabetes insipidus, psychological comorbidities, even with proper management using desmopressin (a synthetic ADH receptor agonist), Inadequate management during hospital admissions, and confusion with "diabetes mellitus," which can result in serious complications. Ultimately, more than 1,000 individuals affected by diabetes insipidus participated in the survey, and their key findings include:

- Hyponatremia commonly arises as a side effect of desmopressin therapy; this study revealed that one in four participants experienced at least one incident of desmopressin-induced hyponatremia requiring hospitalization.
- Patients utilizing a Desmopressin Escape Method (a strategy where they postpone their desmopressin dose once weekly until polyuria begins) showed a lower rate of hyponatremia (22%) compared to those unaware of this method who followed a regular dosing schedule (34%).
- A quarter of patients faced difficulties acquiring desmopressin during hospitalizations, mainly due to drug unavailability in over half of these instances. Moreover, one in seven did not receive either desmopressin or intravenous fluids while fasting. These individuals displayed classic symptoms of dehydration and are thus at increased risk for life-threatening hypernatremia.
- Eighty percent indicated that healthcare providers had mistakenly classified their condition as "diabetes mellitus" at least once; additionally, 85% expressed interest in renaming their condition.
- One-third reported experiencing psychological challenges linked to their illness, while 64% noted a reduced quality of life. (5).

Conclusion

A variety of names were suggested for the condition. It was evident that the term 'diabetes' in 'diabetes insipidus' should be eliminated. However, 'Pituitary Insipidus' was first suggested, but etymologists found it to be a mismatch, while endocrinologists felt it misrepresented the illness. The term 'ADH Deficiency,' which could be abbreviated as ADHD, risked being confused with another prevalent disease (attention deficit hyperactivity disorder). Similarly, 'Vasopressin Deficiency,' shortened to VD, could misleadingly suggest a sexually transmitted disease (Venereal disease).

Endocrinologists sought a name that clearly described patients either resistant to or deficient in the hormone. Ultimately, they agreed on the terms 'arginine vasopressin deficiency (AVP-D)' and 'arginine vasopressin resistance (AVP-R).'

Although 'diabetes insipidus' will continue to appear in literature for some time, accompanied by its newer designation to indicate continuity—it is anticipated that it will gradually fade away soon.

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