Central diabetes insipidus from a patients' perspective: management, psychological co-morbidities and re-naming of the condition

Cihan Atila[1,2], Paul Benjamin Loughrey[3,4], Aoife Garrahy[5], Bettina Winzeler[1,2], Julie Refardt[1,2], Patricia Gildroy[6], Malak Hamza[7], Aparna Pal[5], Joseph G Verbalis[13], Christopher J Thompson[9,10], Lars G Hemkens[1,2], Steven J Hunter[3], Mark Sherlock[9,10], Miles J Levy[7], Niki Karavitaki[11,12], John Newell-Price[8], John A H Wass[5] and Mirjam Christ-Crain[1,2]

INTRODUCTION

Central diabetes insipidus (cDI) is a rare neuroendocrine condition. Data about treatment-related side effects, psychological co-morbidities, and incidence of incorrect management due to lack of awareness amongst medical professionals are scarce and limited to small studies.

METHODS

Methods: Anonymous web-based survey, conducted via the website of the Department of Clinical Research, University Hospital Basel, Switzerland.

Participants: Patients with cDI were invited to participate in this 10-minute online survey.

Objectives: Questions comprised of five sections: 'patient characteristics', 'management as in- and out-patients', 'psychological co-morbidities', and 'knowledge and awareness among medical professionals and re-naming of cDI'.

RESULTS

Patient characteristics

1034 patients with cDI, 47%(n=488) with isolated posterior and 53%(n=546) with combined anterior/posterior pituitary dysfunction. Median [IQR] age was 42y [32-53]. Median duration of cDI was nine [3-19] years.

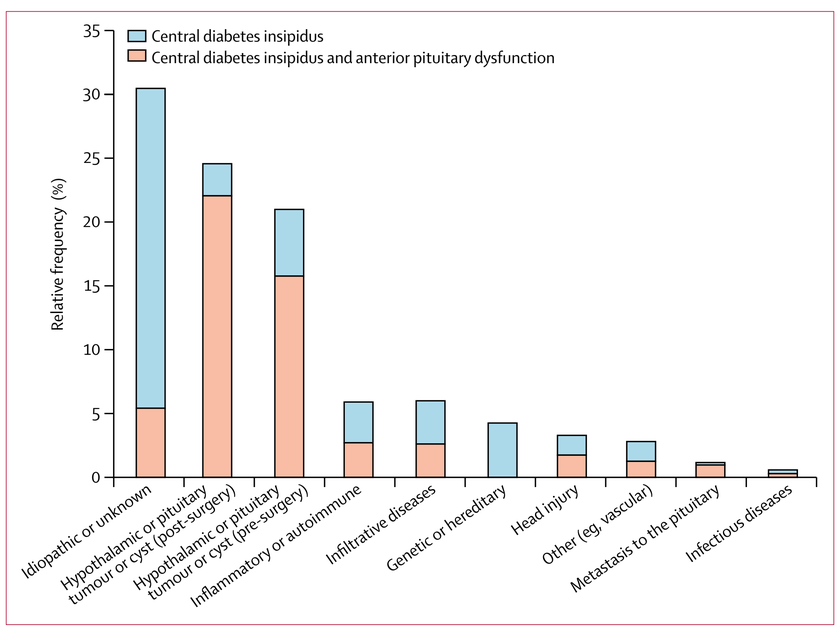


Figure 1: **Causes of central diabetes insipidus**
The proportion of participants with isolated central diabetes insipidus cases and proportion with combined central diabetes insipidus and anterior pituitary dysfunction due to each clinical cause.

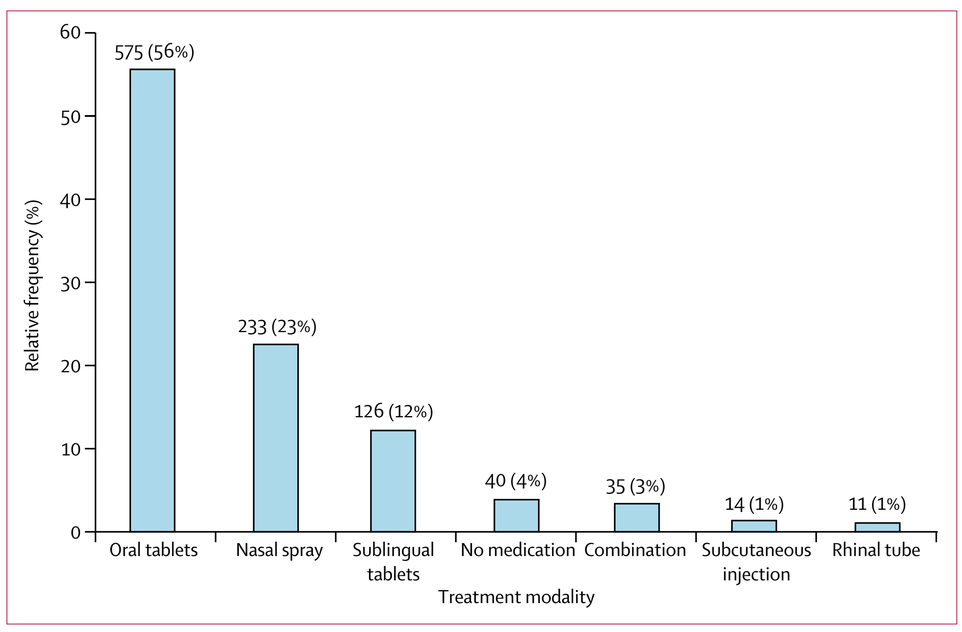


Figure 2 **Type of desmopressin preparation**
Bar plots represent the proportion of each desmopressin preparation.

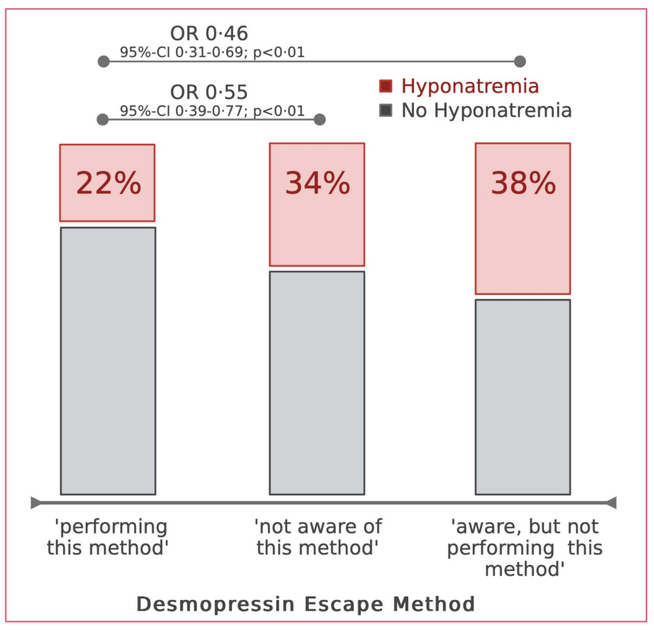


Figure 3 Hyponatremia prevalence
Bar plot represent prevalence of hyponatremia according to desmopressin escape performance

	Full dataset (n=1034)	Participants with isolated posterior pituitary dysfunction (n=488)	Participants with anterior and posterior pituitary dysfunction (n=546)
Psychological problems or changes since diagnosis	369 (36%; [33–39])	173 (35%; [31–40])	196 (36%; [32–40])
Heightened anxiety	258 (25%; [22–28])	115 (24%; [20–27])	143 (26%; [23–30])
Sleep disturbance	263 (25%; [23–28])	113 (23%; [19–27])	150 (27%; [24–31])
Depressed mood	239 (23%; [21–26])	99 (20%; [17–24])	140 (26%; [22–29])
Stress management disturbance	181 (18%; [15–20])	86 (18%; [14–21])	95 (17%; [14–21])
Change in eating habits	168 (16%; [14–18])	82 (17%; [13–20])	86 (16%; [13–19])
Change in personality	124 (12%; [10–14])	51 (10%; [8–13])	73 (13%; [11–16])
Documented psychological condition after the diagnosis	111 (11%; [9–13])	41 (8%; [6–11])	70 (13%; [10–16])
Reduced quality of life after the diagnosis	660 (64%; [61–67])	308 (63%; [59–67])	352 (64%; [60–68])
Social activities	538 (52%; [49–55])	249 (51%; [47–55])	289 (53%; [49–57])
Recreation and fun	493 (48%; [44–51])	234 (48%; [44–52])	259 (47%; [43–52])
Physical wellbeing	476 (46%; [43–49])	218 (45%; [40–49])	258 (47%; [43–51])
Mental wellbeing	414 (40%; [37–43])	192 (39%; [35–44])	222 (41%; [37–45])
Subjective rates on a visual analogue scale, median [IQR]			
QoL*†	6 (4–7)	6 (4–8)	6 (4–7)
Ability to trust*†	7 (4–8)	7 (4–8)	7 (4–8)
Social interaction*†	7 (5–8)	7 (6–8)	7 (4–8)
Sexual arousal*†‡	3 (2–7)	4 (2–8)	3 (1–6)
Anxiety level in general life*§	6 (3–8)	6 (3–8)	6 (3–7)

Data presented in median [IQR] and n (%; [95%-CI]). *Rated on a visual analogue scale from 0 (minimum, no, or none) to 10 (maximum or extreme). †Low score on this parameter reflects more adversely affected. ‡Answered by 819 patients. §High score on this parameter reflects more adversely affected. QoL=quality of life.

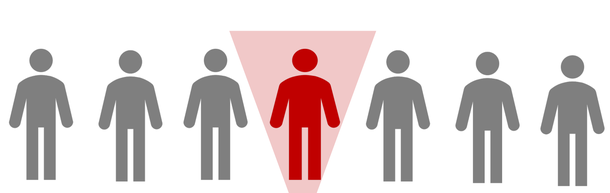
Table **1 Psychological comorbidities**

Knowledge and awareness among healthcare professionals

80% (n=823) indicated that health-care professionals had confused their condition with 'diabetes mellitus' on at least one occasion.

84% (n=869) think that physicians in general (during routine or emergency hospital admissions) have insufficient understanding of cDI and rated the general knowledge of physicians with **two** [IQR 1-4] out of ten possible points.

85% (n=884) preferred a re-naming of the condition; amongst those, the most common suggestion was **'vasopressin deficiency'** or **'AVP deficiency'.**



Hyponatremia prevalence

'Desmopressin escape method', an approach to delay or omit a desmopressin dose to allow aquaresis.

67% performed this method
21% were not aware of this approach
12% were aware, but did not use this

Patients **using desmopressin escape** had a significantly **lower prevalence of hyponatremia leading to hospitalization** compared to those not aware of this method.

In-patient management

During hospitalisation, around **one in seven patients** (n=71/535) did not receive desmopressin while in a fasting state (*'nil by mouth' / 'nil per os'* state) without intravenous fluid replacement and reported symptoms of dehydration.

CONCLUSION

This is the largest survey in patients with cDI, reporting high rates of treatment-related side effects, mismanagement during hospitalisation, psychological co-morbidities, and a clear desire for re-naming the condition. Our data are the first to demonstrate the value of routinely omitting/delaying desmopressin, to reduce prevalence of hyponatraemia.

cihan.atila@usb.ch

@ClinNeuroEndo

[1]Department of Endocrinology, Diabetology and Metabolism, University Hospital Basel, Switzerland; [2]Department of Clinical Research, University Hospital Basel, University of Basel, Switzerland; [3]Regional Centre for Endocrinology and Diabetes, Royal Victoria Hospital, Belfast, UK; [4]Patrick G Johnston Centre for Cancer Research, Queen's University Belfast, UK; [5]Oxford Centre for Diabetes, Endocrinology and Metabolism, Churchill Hospital, Oxford, UK; [6]Administrator and Patient Advocate for the Facebook Group: *Got Diabetes Insipidus?*; [7]Department of Endocrinology, University Hospitals of Leicester, Leicester, UK; [8]Dept of Oncology and Metabolism, University of Sheffield, Sheffield, UK; [9]Department of Endocrinology, Beaumont Hospital, Dublin, Ireland; [10]Royal College of Surgeons in Ireland, Dublin, Ireland; [11]Institute of Metabolism and Systems Research, University of Birmingham, Birmingham, UK; [12]Centre for Endocrinology, Diabetes and Metabolism, Birmingham Health Partners, Birmingham, UK; [13]Georgetown University Medical Center, Washington, DC, USA