Comorbidities are the norm for steroid-dependent patients and predispose to adrenal crisis

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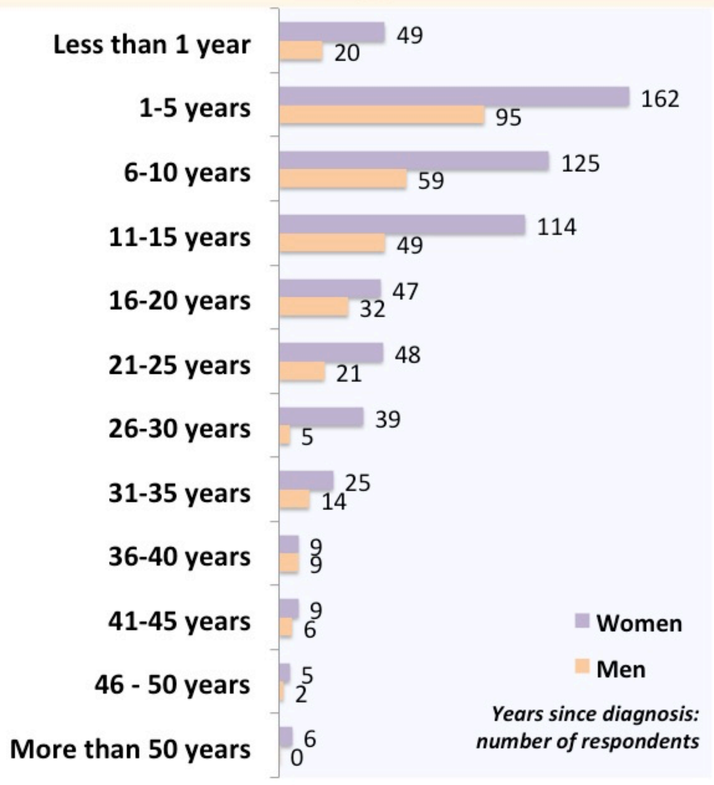
INTRODUCTION

Respondents reported an average of 12.2 years since diagnosis, for a total of 11,746 patient years since diagnosis



Steroid-dependence is a life-long condition with a risk of premature mortality from undertreated adrenal crisis, hospital omission of steroids, or running out of maintenance drugs at home.

We invited members of the main UK support groups representing steroid-dependent patients to complete an online questionnaire about their experiences of adrenal crisis. Members of the ADSHG, Pituitary Foundation, Living with CAH and AMEND took part.

Respondents (N=1046) were asked to provide demographic information that explored predisposing factors, including comorbidities and length of repeat prescription for their essential steroid drugs.

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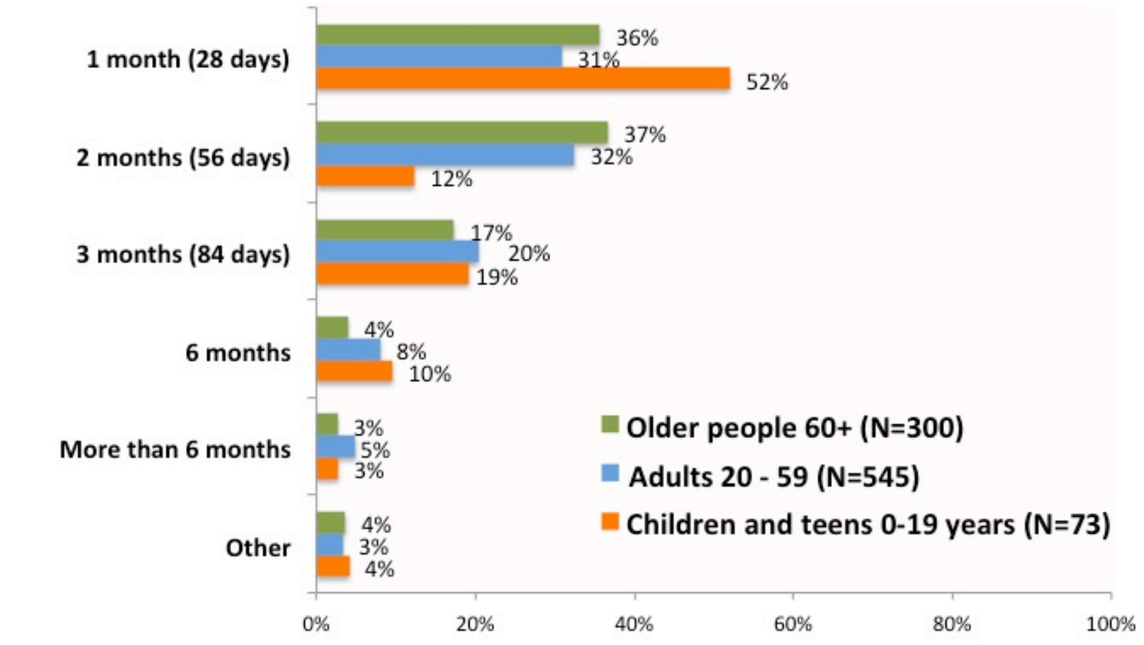
FINDINGS

Those most vulnerable to running out of essential steroid medication are typically on the shortest repeat prescription length



Only 22% had registered with their ambulance trust for priority response in the event of a 999 callout. 40% said they had not been not aware it was possible to register, and 38% said they had not yet been motivated to do so.

13% did not wear medical jewellery.

Paediatric and geriatric patients were more likely to be on the minimum length 28 day repeat, while adults of working age were more likely to receive an extended length repeat from 2 – 6 months.

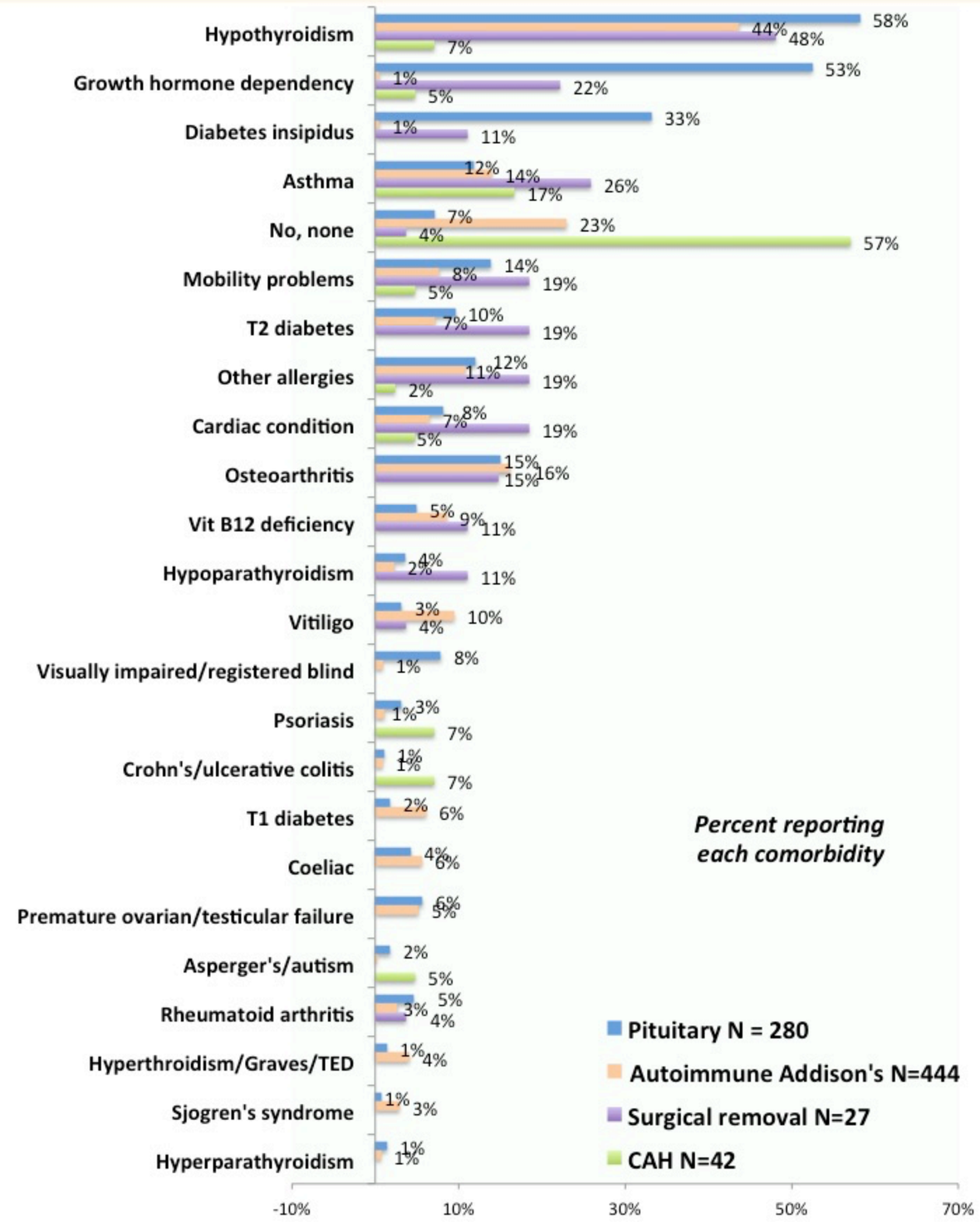
- *"I have requested longer, but my GP will only prescribe a month's supply."*
- *"Despite requesting a 3 month script, our GP surgery insists they are only allowed to prescribe for one month, regardless of the fact this is a lifelong condition. I do have a month in hand though, so have 2 months available (which should be sufficient in case there is a need to increase dose)"*
- *"I was prescribed 2 months on leaving hospital but my GP reduced it to 28 days.*
- *"My GP will NOT prescribe more than two months. She says that she is not allowed to, even though my consultant disagrees with her."*
- *"My last prescription was signed by another doctor at the same practice who was not willing to give more than 3 months."*
- *"4 months."*
- *"It was 4 months for the first 10 years but have now moved to 6 months."*

CONCLUSIONS

These findings emphasize the vulnerability of steroid-dependent patients to adrenal crisis and the importance of good patient education about self-management of their multiple drug dependencies.

FINDINGS

Comorbidities are the norm for steroid-dependent patients



Comorbidities, which are recognised to increase vulnerability to adrenal crisis, were the norm for patients steroid-dependent from any cause. 23% of autoimmune Addison's patients and 7% of pituitary patients reported no additional conditions. 57% of CAH replies, mostly from parents of a paediatric patient, reported no additional conditions; 16% identified asthma.

Hypothyroidism was the most common comorbidity, reported by 44% - 58% of patients with autoimmune Addison's or a pituitary condition. Growth hormone dependency was reported by 53% of pituitary patients.

Diabetes insipidus, which predisposes to adrenal crisis due to instability of the fluid balance, was reported by 33% of pituitary patients.

Asthma, another condition predisposing to adrenal crisis, was reported by 12% of pituitary, 14% of autoimmune Addison's and 26% of patients whose adrenals had been surgically removed.

Osteoarthritis was reported by 15% of pituitary and 16% of autoimmune Addison's patients.

Pituitary patients reported more mobility problems (14%) than those with Addison's (8%). 19% of those whose adrenals had been surgically removed reported both mobility and cardiac problems.

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