



Medication management and quality of life in patients with primary adrenal insufficiency

Primary adrenal insufficiency is a relatively rare endocrine condition requiring life-long glucocorticoid and mineralcorticoid replacement therapy. Unlike other endocrine conditions – such as diabetes – complications associated with early mortality are unusual and well-medicated patients can expect to have a normal life span. Nevertheless, patients typically report a variety of symptoms which reduce their quality of life.

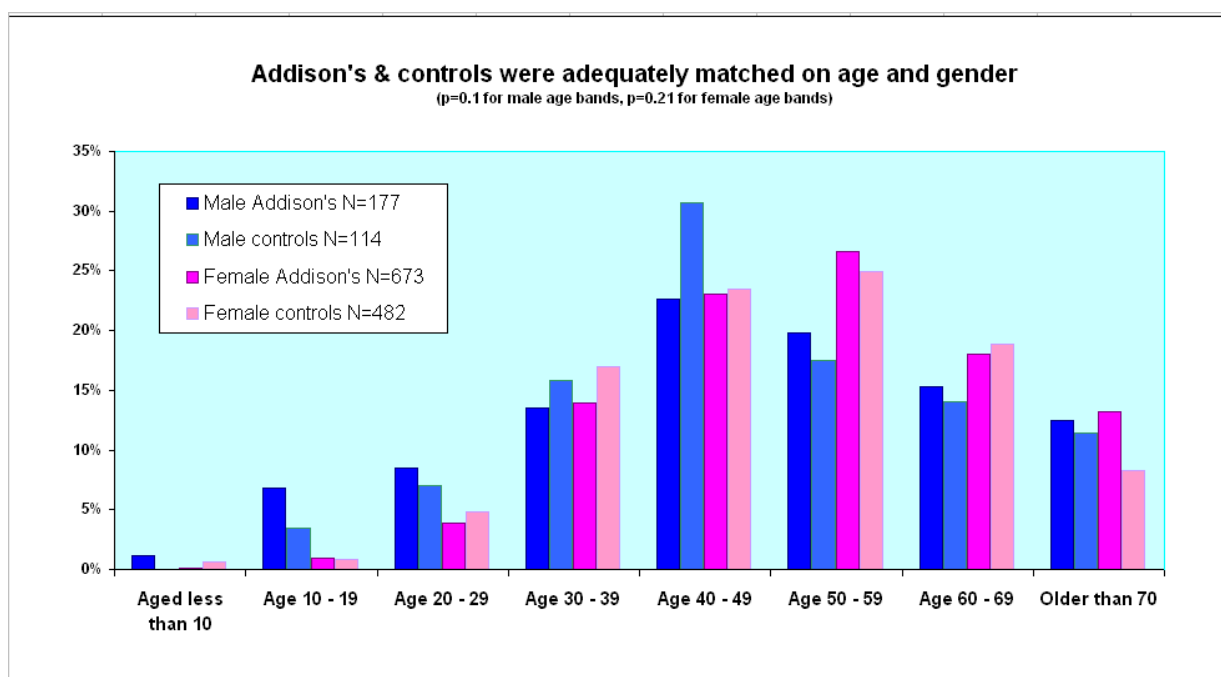
Data from an international survey conducted in 2003 across the UK, Canada, Australia and New Zealand (N = 851) , shows that primary adrenal insufficiency patients consistently report ongoing symptoms typically associated with steroid insufficiency. For example, nearly two-thirds experience fatigue regularly or almost always. One-quarter experience salt cravings and muscle weakness this frequently. Nearly one in five reported ongoing hyperpigmentation and 11% ongoing nausea. One-third said their condition affected their ability to participate in social activities.

Despite this, a significant proportion of patients appear to be mildly over-medicated. We derived Body Surface Area for survey respondents taking hydrocortisone and identified a mean dose of 13.9mg per metre squared for men, and a mean dose of 14.3mg per metre squared for women, where an ideal dose would be 10 – 12mg per metre squared per day.

Responses from primary adrenal patients were compared to those of a matched control group (N = 596), who consistently reported fewer symptoms as well as greater participation rates in paid employment and recreational activities. For example, 10% of those with hypoadrenalism reported they were unable to work through disability or illness, compared to 1% of the matched control group.

This is the largest adrenal insufficiency patient survey to date and shows significant morbidity compared to carefully matched controls. These symptoms need attention and may be treatable using modern methods of hormone replacement.

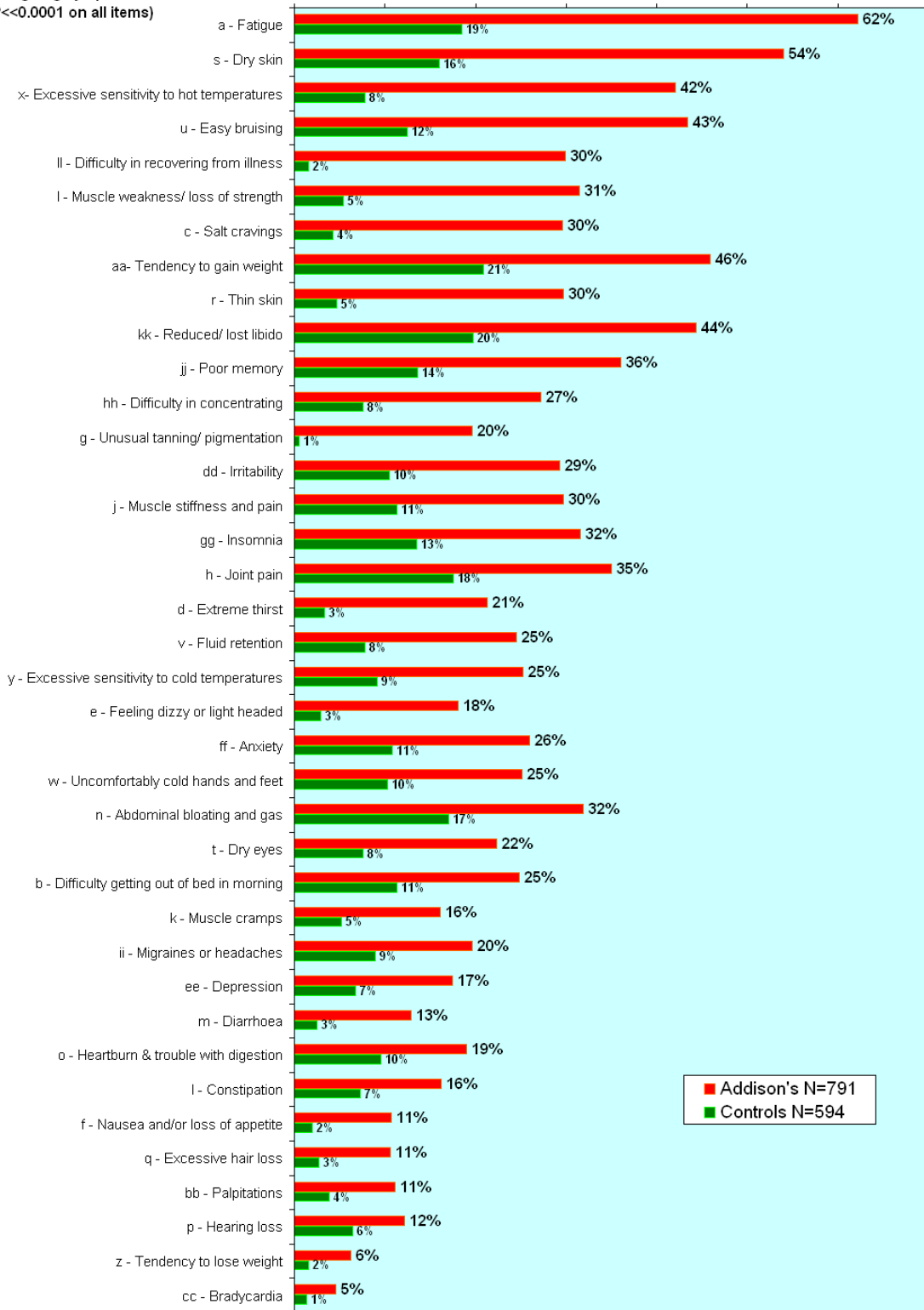
This is the largest patient survey of adrenal insufficiency to date and draws on data from four countries: Australia, Canada, New Zealand, the United Kingdom



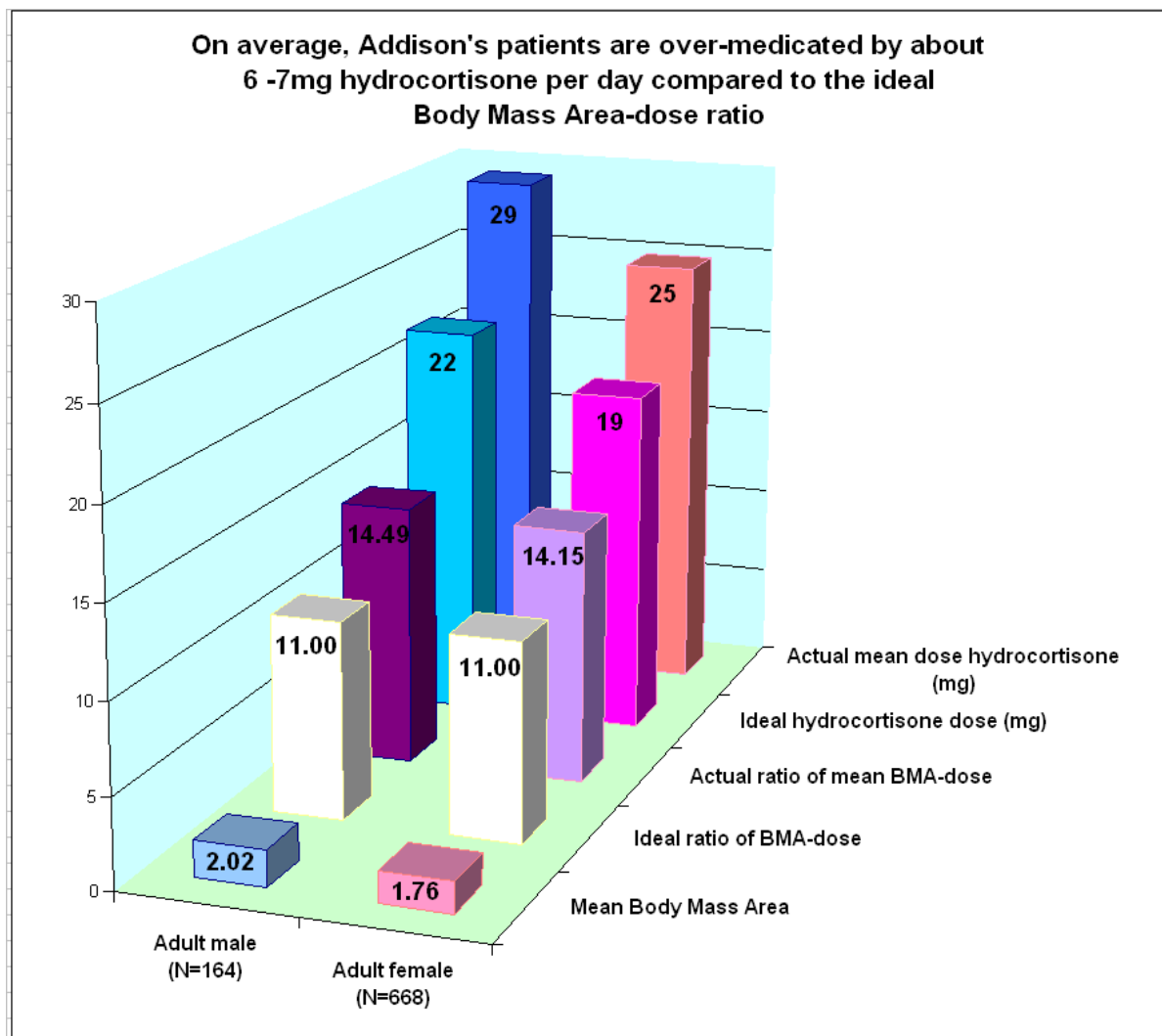


Primary adrenal insufficiency patients experience reduced quality of life on every item tested, compared to age and gender-matched controls

Ongoing symptoms
($P < 0.0001$ on all items)



Percentage reporting regularly or almost always
(Items sequenced by size of gap Addison's - controls)



Quality of life is impaired for primary adrenal patients, despite adequate glucocorticoid replacement

For a discussion of Cortisol Production Rate (CPR) and guidelines for glucocorticoid replacement therapy see for example: Kraan GPB et al, The daily cortisol production reinvestigated, **Journal of Clinical Endocrinology & Metabolism** 1998, Vol 83 No 4: 1247-52. Brandon DD et al, Cortisol production rate measurement, **Steroids** 1999, Vol 64 No 6: 372-8, found a range of actual CPR varying from 2.7 – 14mg/metre squared per day.

The ideal mean BMA-dose ratio of 11mg/metre squared per day we quote should be regarded as indicative only and should not be used to determine individual requirements, which can vary from the norm.

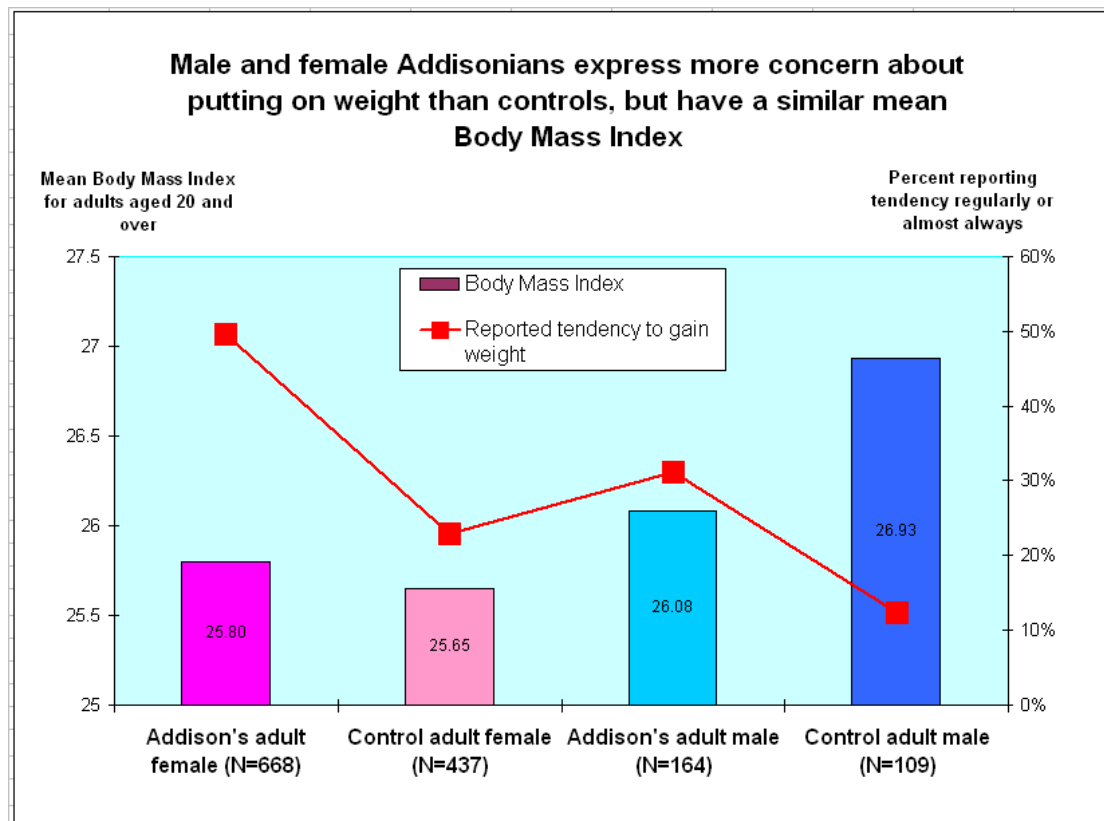
International Addison's survey 2003.

Quality of life data excludes cases of secondary (pituitary) adrenal insufficiency.

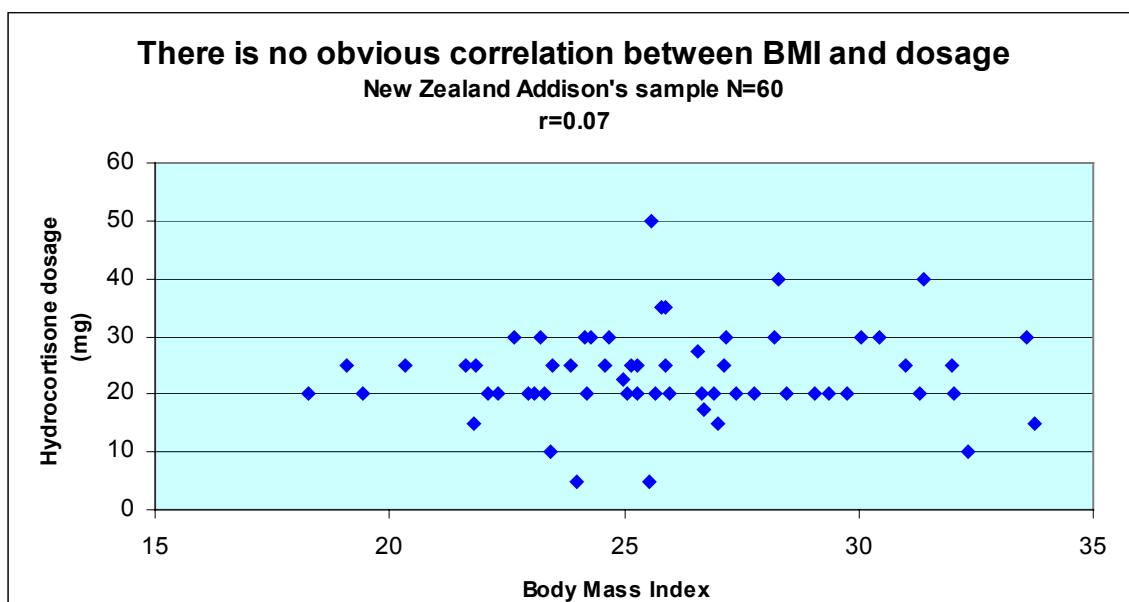
Participating countries: Australia, Canada, New Zealand, UK.

Principal authors: Professor John Wass, Katherine White, Alyson Elliott, Sarah Baker.

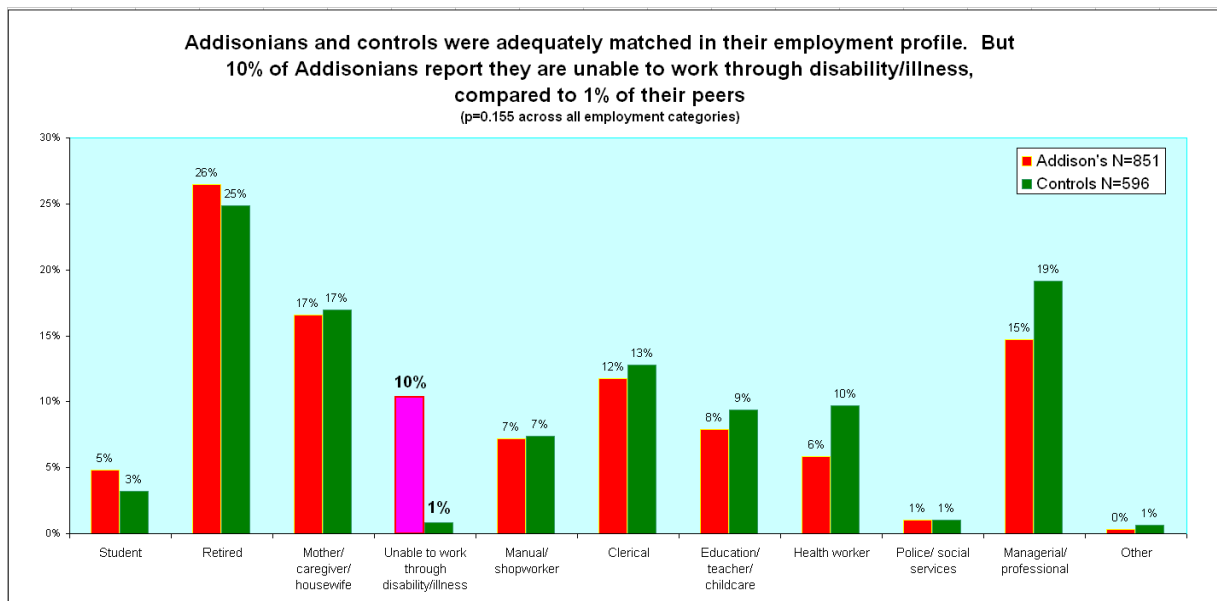
Contributing advisers: Dr Wiebke Arlt, Professor Krishna Chatterjee, Dr Mike Crosson, Dr Ellie Gurnell, Dr Penny Hunt, Dr Trevor Howlett.



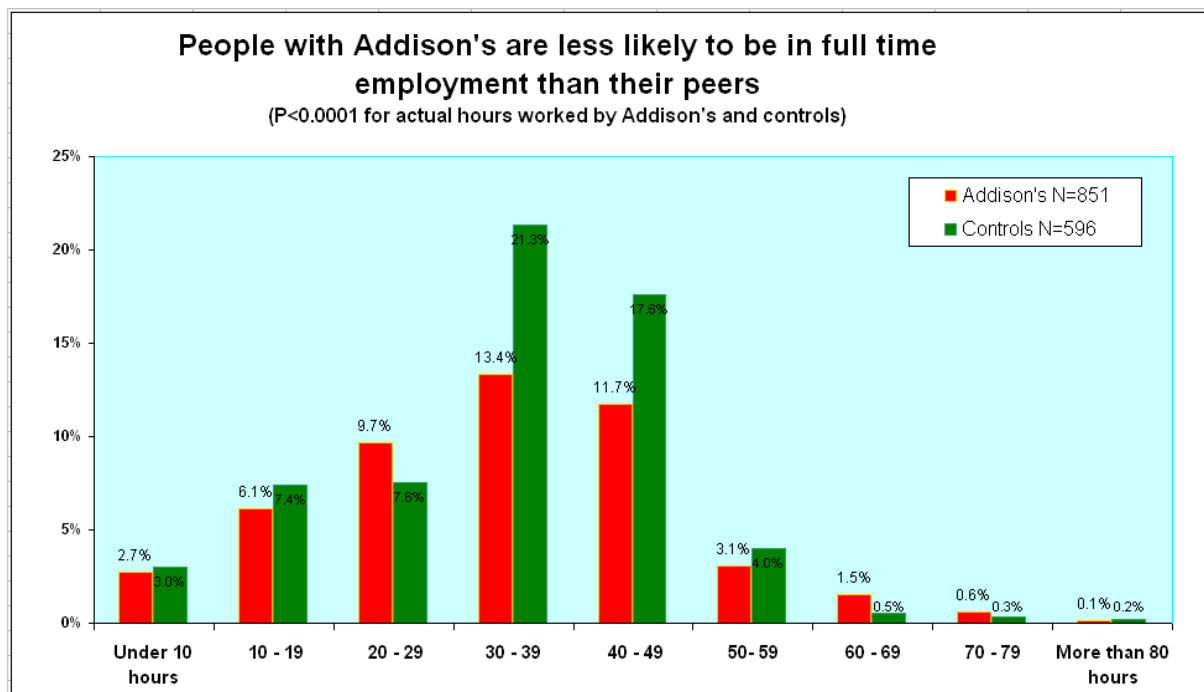
Addison's patients are concerned about weight gain but do not show genuine signs of a problem with weight control.



Higher glucocorticoid doses do not appear correlated to weight gain in Addison's patients



Living with Addison's appears to have some impact on patients' ability to participate fully in employment and recreational activities



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The Addison's Disease Self-Help Group is a registered charity, #1106791.

<http://www.adshg.org.uk>