SAT 488

Follow-Up Intervals in Cushing's Disease: A Multi-Center Study in 230 Patients

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* Potential conflict of interest may exist. Please refer to the Meeting App.

BACKGROUND

- Cushing's disease (CD) has an annual incidence of up to 8 per million in the US.[1]
- Uncontrolled CD leads to significant morbidity and mortality.[2]
- To diagnose Cushing's disease (CD) recurrence and mitigate increased morbidity/mortality risks, long-term follow-up is essential. [3,4]
- Real-world follow-up interval patterns of patients with CD may supplement existing recommendations on appropriate follow-up of such patients with CD in clinical practice.

OBJECTIVE

- The aim of this study was to determine the length of time that had elapsed since the last visit, in CD patients treated in the US .

METHODS

Study Design and Data Source

- Retrospective data collected from medical records at 8 US pituitary/endocrine centers, selected based on volume of CD patients, location, and patient diversity.
- The study was approved by institutional review boards.

Patient Selection Inclusion Criteria

- Diagnosed with CD or CD recurrence within past 20 years; AND
- ≥18 years old at diagnosis.

Data Collection

- Data (collected from onset of Cushing's Syndrome (CS) symptoms through 2014 by trained abstractors) included:
  - Demographics (age, sex, race/ethnicity)
  - Disease characteristics: onset of CS symptoms, date of diagnosis of CD, CD recurrence, biochemical status
  - CD treatments delivered at study centers and local practices
  - Comorbidities (prevalence was based only on comorbidities reported at the study centers)
  - Final disposition (date of last visit, evidence of transfer of care, insurance status at last visit)
- Data quality measures included rigorous abstractor training, data quality checks, and follow-up abstraction for inconsistencies and missing entries.

Statistical Analysis

- Descriptive results stratified by length of time since last visit: ≤1 year; 1-2 years; and >2 years.
- Analyses performed with SAS® version 9.4 (SAS Institute, Cary, NC). .

RESULTS

Patient and Follow-Up Characteristics

- Of the 230 patients studied, 124 (54%) were last seen ≤1 year, 42 (18%) within 1-2 years, and 64 (28%) were last seen >2 years prior (Table 1).
- Transfer of care, with presumed follow-up elsewhere, was documented in 5 patients (4%) with a visit ≤1 year prior, 8 (19%) with last visit 1-2 years prior, and 23 (36%) with a last visit >2 years prior (Table 1).
- Patients with a last visit >2 years prior (n=64) compared to those seen ≤1 year prior (n=124):
  - Were more likely to be female (89% vs. 74%)
  - Had a lower comorbidity burden (median number of conditions: 4 vs. 5)
  - Had similar proportions of insured patients (89%)
  - Were less likely to have radiotherapy (3% vs. 19%) or pharmacotherapy (20% vs. 33%)
  - Had similar median age (44 vs. 46 years) and race distributions (e.g., both 69% white)
- Recurrent or residual disease was most commonly observed in those seen ≤1 year (48%) than in patients last seen 1-2 years (29%) or >2 years prior (28%) (Table 1).

Treatment for Cushing's Disease

- 96% had surgical excision as first-line therapy.
- Among 89 patients with residual/recurrent CD, 45 (51%) received pharmacotherapy, 29 (33%) radiatiotherapy, and 16 (18%) adrenalectomy.
  - Fewer patients with a last visit >2 years prior had radiotherapy (11%) compared to those seen within 1 year (41%) (Table 2).
  - Median elapsed time from start of most recent type of therapy to last visit was shorter among patients last seen >2 years prior compared to those seen within 1 year, 8.1 vs. 14.9 months, respectively.

Table 1. Patient Characteristics, by Follow-Up Interval

	Time since last visit		
Characteristics	**≤1 year**	**1-2 years**	**>2 years**
N (%)	124 (54)	42 (18)	64 (28)
Age at last visit (years), mean ± SD	46 ± 13	45 ± 14	44 ± 13
Median [range]	46 [23-83]	43 [21-73]	44 [19-79]
Female, n (%)	92 (74)	32 (76)	57 (89)
Race, Caucasian, n (%)[a] Black Other	86 (69) 10 (8) 4 (3)	25 (60) 1 (2) 1 (2)	44 (69) 3 (5) 4 (6)
Ethnicity, Hispanic/Latino, n (%)[a]	23 (21)	6 (23)	12 (24)
No. of comorbidities, mean ± SD[b]	5.5 ± 3.4	3.7 ± 2.7	3.7 ± 2.7
Insurance status, Insured, n (%)[a]	109 (89)	39 (93)	55 (89)
Recurrent/residual disease, n (%)	59 (48)	12 (29)	18 (28)
Time from diagnosis to last visit (years), median [range]	3.9 [0.0-27.4]	3.5 [0.0-18.8]	1.6 [0.0-21.7]
Follow-up duration at study centers (years), median [range][c]	2.7 [0.0-27.5]	1.5 [0.0-15.5]	1.1 [1.0-21.7]
Documented transfer of care, n (%)	5 (4)	8 (19)	23 (36)

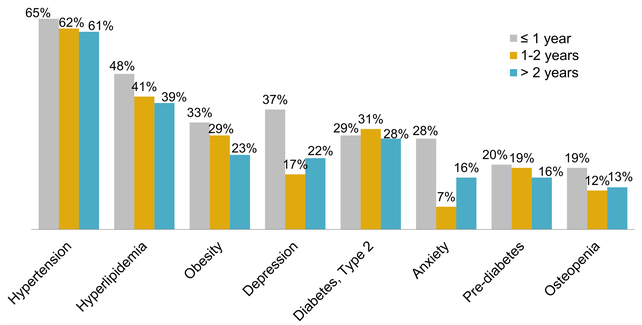
[a] Percent among non-missing observations.
[b] Based on comorbidities reported at study centers.
[c] From first to last visit.

Table 2. Treatment for Recurrent/Residual CD[a]

	Time since last visit		
Patients with recurrent/residual CD	**≤1 year**	**1-2 years**	**>2 years**
No. (%) of patients	59 (66)	12 (13)	18 (20)
Pharmacotherapy	34 (58)	3 (25)	8 (44)
Radiotherapy	24 (41)	3 (25)	2 (11)
Adrenalectomy	11 (19)	1 (8)	4 (22)
Time from last treatment to last visit (months), median [range]	14.9 [0.0-196.2]	25.1 [0.0-137.0]	8.1 [0.0-94.0]

[a] Any therapies before last visit at study site.

Figure. Prevalence of Individual Comorbidities, by Follow-Up Interval



LIMITATIONS

- Data from outside the study centers may have been inconsistently captured.
- Care at the study centers may not be representative of care throughout the US.

CONCLUSIONS

- **Many patients with CD went more than 1 year without a visit at these pituitary centers.**
- **A majority did not have transfer of care documented.**
- **Although follow-up elsewhere may have occurred without documentation, the absence of documentation itself may represent an opportunity for quality improvement efforts.**
- **The ideal period for follow-up of CD has not been established, although delay in follow-up may place patients at risk of undetected recurrence, progression, or development of comorbidities, unless appropriate care is received outside the study centers.**

References

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