Patterns of "Hemp Extract" Usage by Utah Patients with Intractable Epilepsy: Results of the Utah Hemp Extract Application Review and Survey

Presentation to the Health and Human Services Interim Committee by Carey Wilson, MD (University of Utah). June 20,

OBJECTIVE: To better understand patterns of use, access limitations, and effects of hemp extract on Utah patients with intractable epilepsy to improve patient care and inform policymakers.

BACKGROUND: After the Utah Legislature passed H.B. 105 in 2014, allowing use of hemp extract for intractable epilepsy, many families began using non-pharmaceutical cannabis products made by marijuana/hemp growers and producers with minimal standardization or usage guidelines. The Utah Department of Health awarded the University of Utah Division of Pediatric Neurology a grant to study the effects of hemp extract usage in Utah and to better understand the experience of these patients.

DESIGN: Three overlapping datasets were employed through retrospective, observational, or survey designs. The "total dataset" provides a complete count of 262 original hemp extract applications and renewals since the passage of HB 105. "Application review dataset" assessed basic usage patterns, effect on seizures, and other benefits or side effects for 140 patients. More detailed data, named "survey dataset," was collected from a subset of 46 patients who replied to a voluntary 12 item usage survey.

STUDY RESULTS:

Total Dataset (n=262):

- 262 Utah patients have obtained hemp extract registration cards since 7/1/2014, with 45% renewing at least once.
- 124 cards are currently active, either as originally issued cards in their first year or renewed.
- The most cited reasons for not renewing were lack of benefit, cost, or access challenges.

Application Review Dataset (n=140):

- Median patient age = 17 years (range 1-74y). Gender divided evenly (50/50%). (No data on 20 applicants, n=120)
- Of the 63 applicants reporting seizure effects, 45 (71%) reported improved seizure burden, including complete seizure control in one child.
- Of the 61 applicants reporting other effects beyond seizure control, only 11 (18%) described one or more adverse effects (usually transient), including increased seizures, diarrhea, or fatigue.
- 29 (48%) of the above-described 61 patients reported other benefits such as better sleep, alertness, or mood. Some adults endorsed decreased anxiety or reduction of other seizure mediations, while some children's families endorsed better language and social skills.
- 22 (17%) of the 133 applicants taking hemp extract reported an actual CBD concentration of the product.

Survey Dataset (n=46):

- 140 patients were mailed a survey and 46 (33%) responded; only 41 (89%) of the 46 respondents reported using hemp
- Of the 38 patients who reported age, 17 (85%) of the 20 pediatric patients and 10 (56%) of the 18 adult participants reported improvement in seizure burden (frequency and/or severity).
- 9 (22%) of 41 survey respondents endorsed adverse effects such as increased seizures, diarrhea, or fatigue.
- 27 (66%) of 41 survey respondents reported other benefits including better sleep, alertness, or mood.
- 23 (56%) of 41 respondents could provide an actual CBD concentration or milligram dosage.
- Most prevalent product: Charlotte's Web (78%).
- Most common dosing: Twice daily (54%).
- Average usage duration: 14 months (range 1-36m).
- Average cost: $177/month (range $40-500/mo).

LIMITATIONS: This study is based on retrospective, observational, self-reporting from patients and caregivers using a variety of non-standardized and unconfirmed hemp extract products.

CONCLUSIONS:

The majority of Utah patients with intractable epilepsy using hemp extract reported improved seizure control with few, generally transient, side effects. Many endorsed more sustained benefits beyond seizure control. Although results are limited by unconfirmed hemp product contents and responder or self-reporting bias, the study can help inform patient care, future research, and legislation regarding use of hemp extract for epilepsy, including the importance of standardized hemp products.

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