

Cannabis in EB – Risks and Potential

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“Cannabis and EB” - What are we talking about?



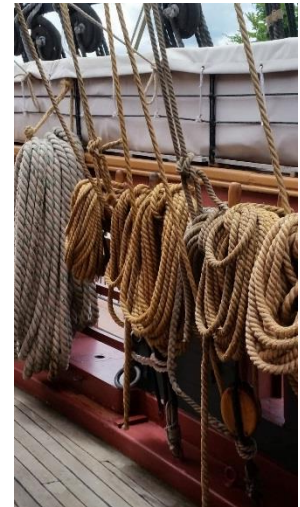
Cannabis

- Cannabis sativa L.
 - subspecies:
 - Cannabis sativa ssp. sativa
 - Cannabis sativa ssp. indica
 - (Cannabis sativa ssp. ruderalis)
 - > 100 diverse sorts
 - vary immensely in THC- and CBD- content
 - industrial hemp: $\text{THC} < 0,2-0,35\%$ ($\text{CBD} > \text{THC}$)
 - marijuana: $\text{THC} > 10-25\%$ ($\text{THC} > \text{CBD}$)



Cannabis sativa L.

- >60 cannabinoids, and other components (e.g. terpene)
- most interesting (and discussed) components:
 - delta-9-tetrahydrocannabinol (Δ^9 -THC)
 - cannabidiol (CBD)
- nutrition: oil (seeds), tea (THC free)
- industrial use: hemp fibre (ropes, clothes)
- recreational use: marijuana, hash
- marijuana = “herbal cannabis”, dried female blossoms, small leaves
- hash/pot = “cannabis resin”, extracted from plant, crude or purified

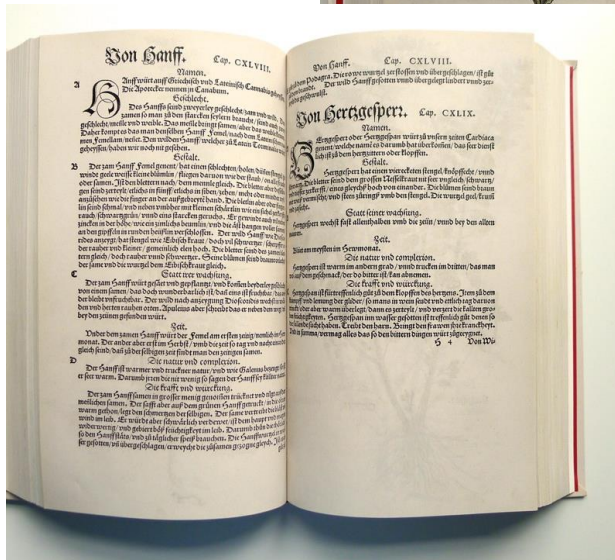


Medical Use of Cannabis sativa L.

- licensed drugs (Austria)
 - Dronabinol® (THC, half-synthetic until 2008, since then herbal extract)
 - Canemes® (Nabilone, THC derivate, synthetic)
 - Sativex® (Nabiximols, herbal extract with standardizes THC and CBD content)
- few indications (severe conditions)
 - chronic, neuropathic pain, spasticity (multiple sclerosis), AIDS (cachexy, loss of appetite), severe cancer pain, few rare diseases
- herbal cannabis/flos cannabis= “medical marijuana”
 - dried blossom and small leaves
 - standardized content of THC and CBD, various concentrations
 - available only in few countries (but changing...)



„The New Herbal of 1543“...



- pain relief (articular gout)
- gangrene
- „swelling“ (skin tumours?)
- earache
- topical use > oral use
- probably industrial hemp
-> CBD high, THC low

Austria

- recreational use: illegal (possession up to 5g allowed...)
- medical use: legal
 - Dronabinol[®], Canemes[®] and Sativex[®]
 - with prescription (in due consideration of regulations for addictive drugs)
 - for few indications: refunding from insurances
 - flos cannabis/herbal cannabis: not yet...
- CBD-only (THC<0,2%) products are easily available (until now)
 - no prescription needed
 - expensive
 - at the moment: “dietary supplement”
 - might change soon...



THC vs. CBD

• CB1-Rezeptorinteraction	++	+/-
• CB2-Rezeptorinteraction	+	+/-
• anti-inflammatory	+	+
• immunmodulation	+	+
• analgetic (chron. pain)	+	+/-
• ZNS		
• anticonvulsive	+	++
• musclerelaxation	++	+
• anxiolytic	+/-	++
• psychotrop	++	-
• antipsychotic	-	++
• antiemetic	++	++
• sedative	+	-
• gastrointestinal		
• appetising	+	-
• GI-motility ↓	++	+



psychoactive



not psychoactive

EB Patient Stories

- RDEB (sev. gen.) patient
- widespread metastazising SCC
- severe pain
- regular mefenamin (this patients choice for years)
- morphines were not as effective as expected and side effects (especially severe fatigue) were not well tolerated
- change to Dronabinol/THC
 - start with 5gtt, slowly increased up to 15gtt per taking
 - -> remarkable pain relief
 - -> no fatigue
 - start with combination with CBD extract (5%), 5-8 gtt
 - -> reduction of Dronabinol to 5-8 gtt per taking was possible
 - -> active life until ~14 days before death



EB Patient Stories

- RDEB (sev. gen.) patient
- started smoking weed in the age of 23 (for recreation)
- noticed that
 - he was more relaxed
 - “some pain issues disappeared”
 - constipation improved
 - eye pain disappeared
 - drier wounds
 - better sleep
 - more energy
 - side effect: a little more lazy...
- now for many years experimenting with other cannabis based products (THC and CBD) with good and satisfying results on itch, pain, woundhealing



EB Patient Stories

- RDEB patient with massive swallowing problems
 - many dilatations (>50)
 - started smoking herbal cannabis (**high THC**) and never ever had any issues or needs for another dilatation
- child, 10 a, with JEB (gen. interm.)
 - 1-2 cups of (**THC-free**) hemp-blossom tea
 - markedly reduced need for ibuprofen
 - relief of night-time itch



EB Patient Stories

- „CBD Hanftee bio“ = hemp-tea
 - leaves and blossoms of industrial hemp, controlled cultures
 - **THC <0,2%, CBD 1,9%**
 - (mild) sleep disorders
- hemp-oil
 - nutritional product
 - **neither THC nor CBD**
 - ointment (combined with shea butter and beeswax)
reduced itch in some patients with milder EB types
- patients who use CBD oil report that they have better sleep, less pain, more energy...



Self Medication with Cannabis Based Products

- inhalation
 - smoking
 - vaporizer or bong
- oral use
 - THC or CBD drops (or combination)
 - canna-butter (e.g. cookies)
 - dried leaflets (tea) and blossoms
 - with added oil or whipped cream
 - hemp oil (no THC, no CBD)
- topical use
 - CBD extract mixed with other oils (moringa oil, avocado oil, coconut oil...)
 - CBD extract mixed with Manuka honey
 - hemp oil (no THC, no CBD)



CAVE: Self Medication and Street Cannabis



- 20 yrs ago: THC:CBD ratio ~10:1
- today: THC:CBD ratio in Marihuana up to **100:1**

Evaluation of Self-Medication?

- effects are believable, but
 - much depending on species of plant
 - varying
 - depending on patients condition
 - not easily transferable
- trial and experimentation
 - little knowledge about use in EB
 - patients try it anyway
 - often without adequate knowledge
 - medical professionals refuse it
 - often without adequate knowledge...
 - ... so patients don't talk about it
- open questions
 - THC and CBD effects are mixed up
 - what is exactly used?
 - natural vs. synthetic ?
 - long term side effects?
- legal aspects and costs have to be considered



Cannabis in EB: Problems

- long term effects of THC ?
- costs
- legal restrictions
- few standardized products
- herbal cannabis not easy to standardize
 - ...although possible
- „street products“
- ideal THC/CBD ratio unknown
 - different ratios for different applications?
- contraindications (for THC)
 - psychiatric diseases
 - schizophrenia, panic attacks, depression,...
 - neurologic disease
 - epilepsy, cramps
 - cardiac diseases



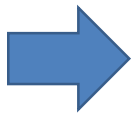
Cannabis in EB: Pros

- application „EB-friendly“
 - inhalative – topical – oral
- CBD and THC have various properties we need in EB care
 - potent pain medication
 - itch relief
 - antiinflammatory potential
 - woundhealing??
- CBD seems to be safe
 - with excellent side effect profile



Children??

- growing evidence for negative effects on brain development and IQ
 - Hall W et al: The health and social effects of nonmedical cannabis use, WHO 2016



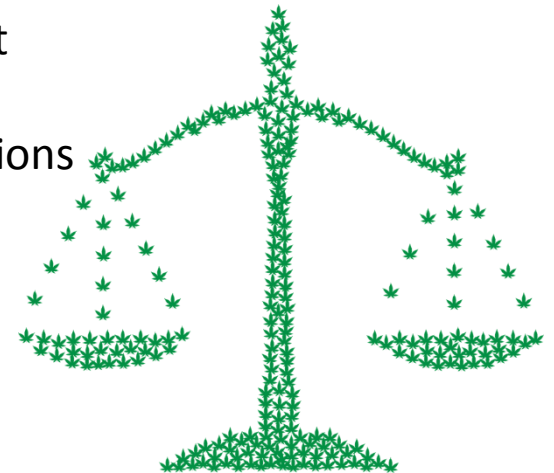
no oral and inhalative THC-containing medicines for children, adolescents and young adults (~age 25)
(despite few specific diseases)

- topical use of low THC/high CBD products ?
- topical use of flos cannabis?
- CBD is promising and expected to be acceptable



Résumé

- we need an open and fact-based discussion about the possibilities of cannabis based medicine in EB
- patients input and experience should be heard
- ratio and interplay of THC and CBD in CBMs are important
- “CBD-only” products might be an option for some indications
- different ways of application are possible
- natural vs. synthetic has to be discussed



! High-quality studies are needed !

Please share your experience!

Thank you.

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