Community Perspectives on the Cascade of Care Model for Medical Cannabis

Debbie Churgai, MA, Grace E. Macalino, PhD, MPH
Why Cascade of Care for Medical Cannabis Access?

- It’s time to get organized and bring evidence-based resources to a legitimate medical treatment for patients!!
- Can highlight all the great work being done to date
Why me?
medical, barriers, providers, norms, attitudes, gender, diagnosis, access, support, cannabis, health, behaviors, frequency, unapproved, word, lack, social, family, seeking, racial, recreational, knowledge, facilitators, wordmark
If you can’t explain it simply, you don’t understand it well enough.

– Albert Einstein
Why is it important to create a model for Medical Cannabis Care?

- Organizing framework for resources, collaboration, shared knowledge
- Legitimacy/credibility as a clinical healthcare population and drug
- Help guide progress and targeting interventions where it is needed most
Medical Cannabis Cascade of Care Model

Stage 1: Diagnosis

Stage 2: Linkage to care

Stage 3: Receipt of drug

Stage 4: Appropriate care
Do you have specific thoughts on the construct of the Cascade of Care Model?
Medical Cannabis Cascade of Care Model

- Better word/phrase to capture Phase 1 other than “Diagnosis”
- Discrete Phases? Anything missing?
- Other thoughts?
Stage 1 - Diagnosis

- Medical Cannabis still illegal
- Restrictive approved diagnoses
- Lack of knowledge:
  - Providers
  - Patients
Stage 1- Diagnosis

● Opportunities/Issues to address
  ○ Inconsistent and/or restrictive eligibility criteria and acceptable conditions by state
  ○ Lack of knowledge regarding proportions within reasons for lack of access
  ○ Evidence-based education and training for providers and patients
  ○ Provider fear related to cannabis prescription and licensing
Stage 1 - Diagnosis: Community perspectives

- I have a hard time with certification courses, as many of the people who put themselves at the helm, know less than many people who have been working in the field for years.

- I feel like I need to get involved in the politics in PA, because they are being very small minded about what is allowed as medical conditions as well.

- The good thing about California--the doctor decides what can be treated with cannabis.

- Differential approved conditions by state
  - FL has a "like or kind" qualifier
  - Our 21 conditions in PA are super strict.
Stage 1 - Diagnosis: Community perspectives

- Collate medical professional lists of providers who understand medical cannabis
- Work together to get federal laws for medical cannabis to avoid differences by state
- Build alliances between those doing work in this area
What experiences do you have to contribute to this phase?
Stage 1: Diagnosis - Patient insights

“CBD-only state. So restrictive that my relative with epilepsy on his 3rd medication (due to side effects) couldn't get a recommendation from his neurologist and they wouldn't direct us to someone who could.”

“Only 'medically legal' in the narrowest sense of the term”.

“I'd like to see physicians get better training or set up a system for assessing valid recommendations”

I have had 3 surgeries due to a spinal injury and they have me on painkillers, but don't offer access to a non lethal plant or it's derivatives. I could cut back on my pain medication by at least 50% or more...But I need legal access to it.
Stage 2 - Linkage to Medical Cannabis Care

- Few eligible prescribing providers
- No standards of care for medical consultation
- Barriers to visiting a prescribing provider:
  - Fear
  - Cost
  - No ins coverage
Stage 2 - Linkage to Medical Cannabis Care

• Opportunities/Issues to address
  o Policy
    ▪ Few caregiver, advocate, or other community resources
    ▪ Slow implementation of state medical cannabis program
    ▪ Prohibitive laws around medical cannabis access for those with a prior record
  o Support
    ▪ Few caregiver, advocate, or other community resources
  o Education and Training
    ▪ Few evidence-based resources linking conditions to specific treatment options
    ▪ Health disparities – those referred and/or those prescribed
Stage 2: Linkage to care – Community Perspectives

- The biggest difficulty I've had with getting cannabis to some seniors, is that they live in facilities that won't allow them to choose their own medicine.

- Challenge of getting certification to rural areas.

- Our biggest issue would be that doctors use the phrase "We are federally funded" as a reason to not certifying individual’s conditions.

- Patients have to doctor shop instead of using their physician of whom they may have been with for years...

- Build alliances between those doing work in this area.
Stage 2: Linkage to care – Community Perspectives

● ...need to set standards for qualified specialist physicians. There is one doctor who has established himself as the specialist for the region, and possibly the state. While his work is good, his interests are limited and limit treatment options for patients.

● I provide specifics to patients. I talk about everything with the patients. If I specialized in neuro, I'm expected to know everything, yet with cannabis, I'm supposed to pretend I don't know anything

● It's hard for people to go an hour and a half to go see a doctor then they have to wait for their card in the mail

● Telehealth opportunities for medical cannabis
What experiences do you have to contribute to this phase?
Stage 2: Linkage to care - Patient insights

“My biggest obstacle was the cost for doctor visits & card registration. Insurance should cover these things. These are real doctors and prescriptions for real medicine. Insurance will cover opioids but not medical marijuana. Makes no sense!”

“High cost of doctors who are willing to recommend - literally it cost over $500 in cash...every 3 months thereafter he wanted $xxx.”

“Recommending doctors know they can charge whatever they want and people have no choice.”
Stage 3 - Receipt of Medical Cannabis

● Gaps
  ○ Few licensed facilities and/or dispensaries
  ○ Limited and inconsistent product availability
  ○ Prohibitive cost/Lack of insurance coverage
  ○ Dispensaries disproportionately located in non-diverse communities
  ○ Negative patient experiences (e.g., finding dispensary, user interface)

● Opportunities/Issues to address
  ○ Fears related to legal status, including prior experience with law enforcement
  ○ Lack of civil protections, e.g. public housing, child welfare, employment, etc.
  ○ Health disparities
Stage 3: Receipt of drug – Community Perspectives

- It would be nice to see a "Good housekeeping seal of approval" for dispensaries as well. This would allow patients to feel confident in choosing where to purchase their medicine.

- Be able to provide caregiver services to be educated on medical cannabis.

- Dispensaries in FL have delivery services. That's most helpful since FL is such a large state.

- Build alliances between those doing work in this area.
What experiences do you have to contribute to this phase?
Stage 3: Receipt of drug - Patient insights

“While we finally have dispensaries, there are few (3 on an island with a million people!)... I live about as far from them as is possible on a small island! It’s an hour+ drive and while a large number of people on our side of the island are patients, the only new one coming is on the other side of the island”

One of the only benefits of having a medical card in Washington state to me is not having to pay sales tax.

One challenge is the lack of medical strains.

There are only recreational stores.
Stage 4 - Appropriate care

- Gaps
  - Few evidence-based resources re: treatment and follow-up regimens
  - Few providers knowledgeable about ongoing care needs
  - No standards of care at dispensaries / negative patient experience
  - Lack of regulatory clarity on new/novel modes of administration, e.g., inhalers, suppository, etc.
  - Lack patient data and research coordination

- Opportunities/Issues to address
  - Lack of ongoing care and monitoring
  - Inappropriate use of cannabis
  - Number of patients seen regularly over time by state
  - Impact of recreational cannabis on medical cannabis access
Stage 4: Appropriate care – Community perspectives

- Patients have to drive hour and a half back to a dispensary a few days later

- I've guided our Wellness Coordinators to ask certain consult questions to help guide patients to the most appropriate choice for them, inside of their recommendation

- Building alliances between those doing work in this area

- Need for lab testing to support consistency of products, an understanding of dosage for products, etc.

- Consensus as an industry around minimum standards
What experiences do you have to contribute to this phase?
Stage 4: Appropriate care - Patient insights

Dosage levels are not adequate for my needs. Pre dosed products too light on medicine. Really appreciate lab testing to assure safe products.

The staff at stores seem to assume that I buy cannabis for recreational reasons more often than not, making it harder to get what I need.
Medical Cannabis Cascade of Care
A place for everyone
How is your specific perspective in cannabis reflected in the Cannabis of Care model?
Medical Cannabis Cascade of Care

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Linkage to care</th>
<th>Receipt of Drug</th>
<th>Appropriate Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy</td>
<td>Policy Regulatory</td>
<td>Labs Dispensary Delivery</td>
<td>Delivery Labs Dispensary Growers</td>
</tr>
</tbody>
</table>

Stakeholders:
Researchers
Patients
Advocates
Providers
Policymakers
Labs
Businesses
Growers, etc.

Discrimination – Stigma – Disparities
Research – Education – Training
Current initiatives

- Marimac Insight Research Institute, Cannabis Center of Excellence
  - Setting research standards/guidelines across the field
  - Gathering of all cannabis research across multiple states, etc.
  - Working with/collaborating with anyone that wants to partner with us
- Cannabis of Care survey planned in partnership with ASA
- Development of patient experience benchmarks and data collection best practice guidelines, aligned with the Cascade of Care
- Developing a repository of data
  - Partnering with those that have data
  - Developing standard data collection practices
From your perspective, where do you see is the greatest need/gap in knowledge or access within the Cascade of Care?
How can you participate?

- Research
  - Patients – we want and need your stories!
  - Providers
  - Businesses
- Donate
- Fund research
- Fundraise *with* us
- Work with us to identify how the Cascade of Care applies to your group/organization
Community Perspectives on the Cascade of Care Model for Medical Cannabis

Debbie Churgai, MA, Grace E. Macalino, PhD, MPH

www.safeaccessnow.org