Social support and discontinuing psychiatric medication

Laysha Ostrow, PhD
International Association of Peer Supporters (iNAPS)
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Learning Objectives

1) active discussion and questions by attendees

2) an opportunity to reflect on results based on attendees’ lived and professional experience

3) engaging in a discussion about data interpretation and preferences for future dissemination and research

Outline

Study background and purpose

Study design and methods

Overview of findings

Social support and discontinuation
REALITY IS A PRISON.

Background & Purpose
Continuum of Involvement & Control in Research

Such expertise has the potential to enhance each stage of the research process and to open new lines of inquiry.
Contributions of Lived Experience to Research Process

Inquiry & Ideas
- Challenging adherence perspective to reflect real choices

Study design
- Ambition + risk vs. Resource limitations + stigma

Measurements
- Survey based on lived experience & work with others

Data collection
- Community participation in recruitment

Interpretation of results
- Reflecting on and sharing early results of data analysis

Dissemination
- Rapidly disseminating results in multiple formats to the public
Alternatives Conference 2017
Building Healing Communities Together
Boston · August 18-21
The College on Problems of Drug Dependence
WHAT HAPPENS WHEN YOU STOP TAKING PSYCHIATRIC MEDICATIONS

According to the people who have tried to do it.

Discontinuing Psychiatric Medications: A Survey of Long-Term Users

Laysha Ostrow, Ph.D., M.P.P., Lauren Jessell, L.M.S.W., Manton Hurd, M.S.N., P.M.H.N.P., Sabrina M. Darrow, Ph.D., David Cohen, Ph.D., M.S.W.

Objective: Individuals undergoing long-term psychiatric treatment frequently choose to stop taking psychiatric medications. To enhance service user choice and prevent undesirable outcomes, this first U.S. survey of a large sample of long-term users sought to increase knowledge about users’ experience of medication discontinuation.

Methods: A sample of 250 U.S. adults with a diagnosis of serious mental illness and a recent goal to stop up to two prescribed psychiatric medications, which they had taken for at least nine months, completed a web-based survey about experiences, strategies, and supports during discontinuation.

Results: About half (54%) met their goal of completely discontinuing one or more medications; 46% reported another outcome (use was reduced, use increased, or use stayed the same). Concerns about medications’ effects (for example, long-term effects and side effects) prompted the decision to discontinue for 74% of respondents. They used various strategies to cope with withdrawal symptoms, which 54% rated as severe. Self-education and contact with friends and with others who had discontinued or reduced medications were most frequently cited as helpful. Although more than half rated the initial medication decision with prescribers as largely collaborative, only 45% rated prescribers as helpful during discontinuation. Of respondents who completely discontinued, 82% were satisfied with their decision.

Conclusions: Discontinuing psychiatric medication appears to be a complicated and difficult process, although most respondents reported satisfaction with their decision. Future research should guide health care systems and providers to better support patient choice and self-determination regarding the use and discontinuation of psychiatric medication.
Repository of shareable research outputs, including datasets and codebooks for:

- PMDR survey data
- Self-employment survey data
- National Survey of Peer-Run Organizations

Provide access to the public to use data not otherwise analyzed by the study team
Study Design & Methods
The Problem

- Individuals undergoing long-term psychiatric treatment frequently choose to stop taking psychiatric medications.
- Most research focuses on adherence to psychiatric medications.
- Little is known about how users experience and cope with discontinuation.
Issue Background

- Increases in psychiatric medications use leads to taking longer than necessary
  - (Insel, 2009)

- Many choose to discontinue medication but no clear guidelines on safe and effective discontinuation
  - (Julius, Novitsky Jr, & Dubin, 2009; Roe & Davidson, 2017)

- Most research focuses on adherence to psychiatric medications, even when advancing “shared decision-making”

- Gap in research on motivations, experiences, processes of discontinuation
  - (Samples & Mojtabai, 2015)
**Goal:** To understand the experience of coming off psychiatric medications through research data.

- What clinical characteristics are associated with meeting discontinuation goals compared to not meeting these goals?
- What circumstances, strategies and sources of support are associated with meeting discontinuation goals compared to not meeting these goals?
- Nationwide survey
- Led by current & former users of psychiatric medication with training in research & clinical practice
- First U.S. survey of a large sample of longer-term users who chose to discontinue

Larsen-Barr M, 2016; Salomon C, Hamilton B, Elsom S, 2014; Read, 2009
Study Sample

- Research participants included 250 adults in the United States who met the following criteria:
  - Labeled with a **psychiatric diagnosis** (psychotic disorder, major depression, or bipolar disorder)
  - In the **last five years**, took prescribed psychiatric medications for at least nine months before trying to come off
  - Had a goal to **completely stop** taking one or two medications in the past five years

- Non-representative purposive sample
Recruitment/Data collection

N = 250

- Social media site
- Email list
- Professional website
- Friend/family
- Provider
- Counselor
- Missing
Survey sections

- Motivations, Strategies, Goals for Discontinuation
- Withdrawal Effects
- Social Supports
- Relationship with Prescribing Health Professional and Psychotherapist
- Medical History / Labels / Diagnoses
- General Health and Wellness
This type of research is useful for...

- Developing hypothesis to test in more rigorous studies
- Identifying potential areas to target for future research
- Recall bias & selection bias

Not intended to be generalizable or definitive!
Overview of Results
In our own voice

It's pointless to blame psychiatrists and even big pharma for pushing psychiatric medications, get angry or advocate coming off. That's how the game is and everyone has to find his own way through it.

Respondent-generated text from PMDR survey:

"I will die with a mental illness, but I don't have to die because of it."
### Demographic

The sample was:
- largely female and middle-aged
- large majority identified as white and non-Hispanic
- Highly educated
- However, over half reported a current annual household income under $40,000, and
- Only 40% were employed full-time

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Mean)</td>
<td>46</td>
</tr>
<tr>
<td>Female</td>
<td>76</td>
</tr>
<tr>
<td>Male</td>
<td>20</td>
</tr>
<tr>
<td>Transgender</td>
<td>2</td>
</tr>
<tr>
<td>Self-identify</td>
<td>1</td>
</tr>
<tr>
<td>White</td>
<td>87</td>
</tr>
<tr>
<td>Black</td>
<td>4</td>
</tr>
<tr>
<td>American Indian</td>
<td>1</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
</tr>
<tr>
<td>Hispanic ethnicity</td>
<td>6</td>
</tr>
<tr>
<td>High school diploma/GED/some college</td>
<td>27</td>
</tr>
<tr>
<td>College degree or more</td>
<td>74</td>
</tr>
<tr>
<td>Full-time employment</td>
<td>40</td>
</tr>
<tr>
<td>&lt;$12,000</td>
<td>17</td>
</tr>
<tr>
<td>$12,000–$39,999</td>
<td>38</td>
</tr>
<tr>
<td>Received public assistance</td>
<td>66</td>
</tr>
</tbody>
</table>
### Clinical

Respondents had:

- Substantial history of involvement in psychiatric treatment
- Hospitalized in a psychiatric inpatient unit
- Extensive exposure to psychiatric medication

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Psychotic disorder</td>
<td>20</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>41</td>
</tr>
<tr>
<td>Depressive disorder</td>
<td>64</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medication class</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Antidepressants</td>
<td>76</td>
</tr>
<tr>
<td>Anxiolytics</td>
<td>56</td>
</tr>
<tr>
<td>Antipsychotics</td>
<td>47</td>
</tr>
<tr>
<td>Mood stabilizers</td>
<td>38</td>
</tr>
<tr>
<td>Stimulants</td>
<td>13</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total lifetime exposure</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;5 years</td>
<td>13</td>
</tr>
<tr>
<td>5–9 years</td>
<td>17</td>
</tr>
<tr>
<td>&gt;9 years</td>
<td>71</td>
</tr>
<tr>
<td>Lifetime psychiatric inpatient stay</td>
<td>65</td>
</tr>
</tbody>
</table>
Medication Status

54% completely discontinued

- Remaining 46% reduced their medication or remained on the same dose or higher

82% satisfied with their decision

- of those who discontinued completely
I had to accept that it was not possible for me to go off and stay off lithium. I did not have any medical support. My erratic behavior was frightening to my friends. My family does not live in the same town where I live...I did not inform them of my decision to go off. A friend of mine was frightened and she called my brother, whom she had never met to tell him I was off my medication.

When coming off of meds, I experienced severe symptoms for a few months, I was tempted to get back on them, but I remained steadfast and my body and mind began to readjust. It was pure hell. But, I made it through.
Reasons for Wanting to Come Off

- Long-term effects: 74%
- Adverse effects: 73%
- Wanted to know who I am: 48%
- Learned about alternative approach: 34%
- Felt Better: 34%
- Drugs not useful: 29%
- Drugs did not work anymore: 23%
- Short term use intended: 13%
- Concerned about reproductive health: 13%
- Advised to come off by prescriber: 8%
- Advised to by health care provider: 5%
- No access to meds: 4%
- Someone in personal life: 4%

Reasons for Wanting to Come Off
Length of Discontinuation Process

- Less than one month: 33%
- One to six months: 31%
- More than six months: 36%
Withdrawal Effects

54% of respondents rated these “severe”
In our own voice

Respondent-generated text from PMDR survey:

“What was the most surprising/most challenging thing you learned in your process of coming off medication?”

I felt like I had been pushed through a door to hell

The most difficult thing I have ever been through

I had tried before and gotten too sick to continue. One day, I forgot and had no adverse effects, so I continued.
Self-Care Strategies

- Self-education: 76%
- Being outdoors: 74%
- Get sleep: 67%
- Expressing feelings: 67%
- Physical exercise: 67%
- Entertainment: 66%
- Mindfulness/meditation: 63%
- Dietary/nutritional changes: 57%
- Hobbies: 57%
- Being in water/baths: 55%
- Journaling/writing: 55%
- Reducing stimulation: 46%
- Over the counter substances: 39%
- Prayer/mantra/chanting: 39%
In our own voice

Respondent-generated text from PMDR survey:

“What helped you the most during the process of coming off medication?”

Being in a quiet, dark room with little stimulation... Sleeping, when possible. Taking showers. Researching all possible information about my medication, knowing what to expect, and knowing that it would pass eventually. Smoking cigarettes, actually helped me.
Treatment engagement during discontinuation

Prescriber
- Saw prescriber: 73%
- Did not see prescriber: 27%

Psychotherapist
- Saw therapist: 48%
- Did not see a therapist: 52%
Social Supports
Social network & isolation

Types of Social Supports

Support available

Helpful

Not Helpful

Don’t have or Didn’t ask

Not available

Discontinuation

Other outcome
Survey Questions

How helpful were the following people when coming off psychiatric medication(s)?

- Helpful, Neutral, Unhelpful, Didn't ask for support, Do not have someone in this role in my life

How supportive was your family [/friends/people you live with] in your decision to come off medication?

- Very supportive, Somewhat supportive, Neutral, Somewhat unsupportive, Very unsupportive, My family was not aware of my decision, Does not apply

In your current social network, how many people do you trust and can you count on in general?
### Types of Social Support

<table>
<thead>
<tr>
<th>Social connection</th>
<th>Bonding supports</th>
<th>Primary supports</th>
<th>Secondary supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Demographics</td>
<td>• Similar social identity</td>
<td>• Intimate &amp; Informal</td>
<td>• Less personal &amp; formal</td>
</tr>
<tr>
<td>• Lifestyle</td>
<td>• Peer supporters, other service users</td>
<td>• Friends, Family</td>
<td>• Coworkers, Religious Community, Clergy</td>
</tr>
<tr>
<td>• Network</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Partnership Status

- Married: 26%
- Never married: 32%
- Partnered not married: 18%
- Divorced: 19%
- Separated: 3%
- Widowed: 2%
Social Network Size

People You Can Trust

- 0-2 people: 16%
- 3-5 people: 38%
- 6-9 people: 16%
- 10+ people: 30%
Availability & Helpfulness: Bonding Supports

- Mutual support group for coming off
- Internet support group for coming off
- Addiction recovery support group
- Other service users
- Peer support worker
- Other discontinuers

Do not have | Helpful | Neutral/Unhelpful | Didn’t Ask
Availability & Helpfulness: Social Support

Do not have  Helpful  Neutral/Unhelpful  Didn't ask

Mutual support group  Addiction recovery group  Peer support workers  Other discontinuers  Religious Community  Clergy  Internet support group  Other service users  Coworkers/colleagues  Friends  Family
Number of Available Supports

Number of Different Types of Supports

% of Respondents

Number of Available Supports

0 1 2 3 4 5 6 7 8 9 10 11

0 5 10 15
Number of Helpful Supports

Number of Different Types of Supports

% of Respondents

Number of Helpful Supports
In our own voice

Peer support, and online support... Also having a lot of space from family.

I would love to have more safe places to go when getting into crisis during coming off, where you get mutual support.

Being able to talk to others that had been thru this. I did that in person but also thru emails and social media. It really helped to have people who understood my right to make my own medical decisions in my life and be positive about my choice.
In our own voice

I learned that people like me. That I don't have to be scared of the "outside." I learned I am free to participate in my community and have value in that community.

It will be worth it in the end. Even though I'm still suffering, I am certain that when I come out the other side life will be so much better and more rewarding.

Even if no one is supportive, it's your body and your life - don't continue to stay medicated solely for others' convenience.
Discussion

To access today’s slide deck please visit:
www.LiveLearnInc.net/media

Laysha Ostrow, PhD, MPP
CEO, Live & Learn, Inc.
www.LiveLearnInc.net
Laysha@LiveLearnInc.net
@LayshaOstrow
www.facebook.com/livelearninc

“The future doesn’t belong to the fainthearted; it belongs to the brave.”

PRESIDENT RONALD REAGAN, after the Challenger explosion