


POST-WITHDRAWAL FROM ANTIPSYCHOTICS: 3,423 RESPONDENT PRELIMINARY DATA

MAD IN AMERICA SEMINAR, MAY 14, 2021



Maastricht University

Did you ever *stop taking antipsychotics*, or try to stop taking them?



We want to **hear from you.**

www.antipsychoticwithdrawalsurvey.com

MAASTRICHT WORLD SURVEY ON ANTIPSYCHOTIC DRUG WITHDRAWAL

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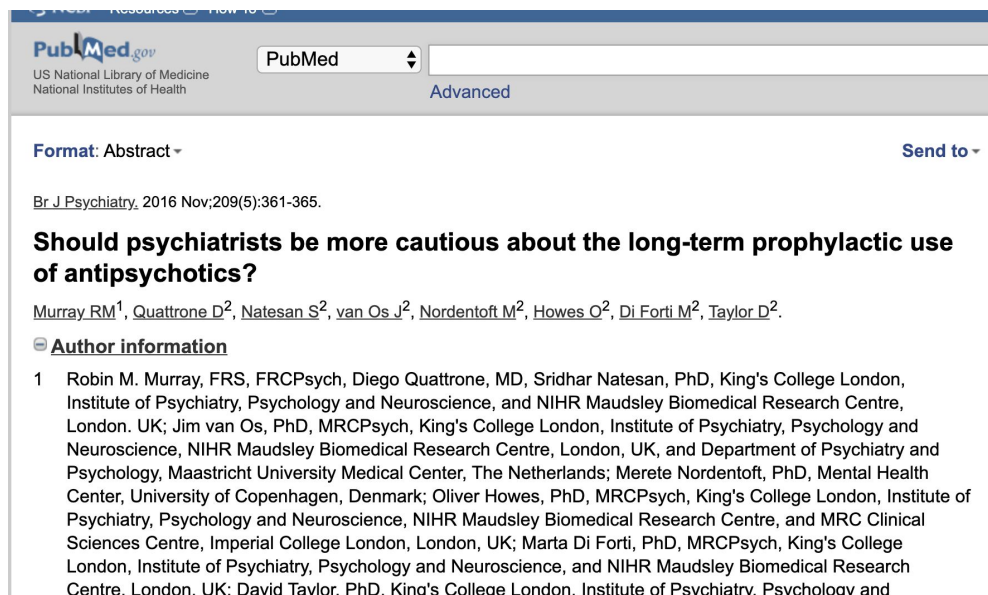
STUDY PARTNERS

- ▶ Maastricht University School for Mental Health And Neuroscience - Netherlands
- ▶ International Institute for Psychiatric Drug Withdrawal - US and Sweden
- ▶ FIOCRUZ - Brazil
- ▶ Crowdsourced survey questions



SURVEY RATIONALE

- ▶ Gap in existing literature on antipsychotic withdrawal
- ▶ Antipsychotics seen as medications for life, prophylactic, now being questioned
- ▶ Focus on antipsychotics makes analysis more concise; more directly calls into question existing standard of drugs for life
- ▶ Sizable sample, international scope strengthens conclusions
- ▶ Mistaken understanding that psychiatric drug withdrawal can be understood solely pharmacologically: emergence of relational and adaptation view
- ▶ Importance of patient experiences
- ▶ Rise of survivor led research
- ▶ Complements similar research now emerging; builds redundancy of similar conclusions



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Format: Abstract - Send to -

[Br J Psychiatry](#). 2016 Nov;209(5):361-365.

Should psychiatrists be more cautious about the long-term prophylactic use of antipsychotics?

[Murray RM](#)¹, [Quattrone D](#)², [Natesan S](#)², [van Os J](#)², [Nordentoft M](#)², [Howes O](#)², [Di Forti M](#)², [Taylor D](#)².

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DESIGN

- ▶ 18+, taken antipsychotics, withdrawn, or tried to withdraw
- ▶ anonymous web survey completed online
- ▶ 167 questions, multiple choice with 15 opportunities for text and narrative replies and 3 open-ended questions
- ▶ ~30 mins to complete entire survey, with key questions front loaded so meaningful data collected even from partial completion

QUESTION AREAS (survey: [HTTPS://BIT.LY/2KHIGSM](https://bit.ly/2KHIGSM))

- ▶ **Demographic information:** *education, employment, homelessness, education, ethnicity, gender*
- ▶ **Diagnosis,** hospital history, and other psychiatric information: *history of trauma, attitudes towards diagnosis*
- ▶ **Medication use** current and past: *people off antipsychotics completely, people taking other psych meds*
- ▶ **Motivations** for withdrawal: *side effects, perceived usefulness of medication, education, life circumstances*
- ▶ **Methods** of withdrawal: *gradual vs. abrupt, intermittent use, pill cutters*
- ▶ **Attitudes** towards and relationship with prescribers and mental health professionals
- ▶ **Strategies** for coping with withdrawal: *role of professionals and family, role of medication use, sleep*
- ▶ **Side effects** and withdrawal effects, including persistent effects
- ▶ **Support** sources during the withdrawal process: *family, professionals, peer/user-survivor movement, community*
- ▶ **Experiences** of withdrawal: *disclosure to others, severity of withdrawal effects, crisis and hospitalization,*
- ▶ **Medical** information: *diseases, current health, disability status, role of medications*
- ▶ **Suicidal and psychotic** current experiences and coping strategies
- ▶ **Open ended** questions: *What did you learn? What would you want professional to do differently?*

RESULTS: 71 COUNTRIES REPRESENTED (n=3173)

USA	1093	Greece	9	Luxembourg	1
UK	445	Colombia	7	Bulgaria	1
Canada	204	Switzerland	7	Hong Kong	1
España	197	Estonia	5	Bahrain	1
Nederland	189	Czech Republic	5	Guatemala	1
Australia	183	Perú	5	Jordan	1
Japan	106	Turkey	4	Senegal	1
France	75	Indonesia	4	Slovakia	1
België	69	Portugal	4	Martinique	1
Ireland	53	UAE	4	Bolivia	1
Norway	50	Serbia	3	Fiji	1
Danmark	46	Austria	3	Bangladesh	1
New Zealand	46	Russia	3	Ukraine	1
Deutschland	41	Lithuania	3	Malta	1
Chile	40	Romania	3	Nicaragua	1
Brasil	34	Philippines	3	Pakistan	1
blank	31	Malaysia	3	Saudi Arabia	1
Sweden	23	Country not list	2	(blank)	
Argentina	21	Hungary	2	Grand Total	3173
India	18	Iceland	2		
Slovenija	17	Algeria	2		
México	17	Croatia	2		
Polska	16	Uruguay	2		
South Africa	16	Lebanon	2		
Israel	11	Singapore	2		
Italia	11	Morocco	1		
Finland	10	Costa Rica	1		
		Cyprus	1		

12 SURVEY LANGUAGES REPRESENTED (n=3244)

EN	(English)	2274
ES-ES	(Spanish)	278
DE	(German)	235
NL	(Dutch)	172
JA	(Japanese)	116
FR	(French)	89
PT-BR	(Portuguese-Brazil)	28
DA	(Danish)	24
PL	(Polish)	10
IT	(Italian)	9
HE	(Hebrew)	4
ES	(Spanish)	3
PT	(Portuguese-Portugal)	2
Grand Total		3244

CONSIDERATIONS FOR THIS PRESENTATION

- ▶ Preliminary data analysis for Mad In America Post Withdrawal seminar May 14, 2021
- ▶ Correlation not causation: full analysis will address endogeneity, confounding variables, multivariate regression, statistical significance p-values
- ▶ Individual experience is not aggregate experience
- ▶ Additional respondents (>350) to be added; collection ongoing
- ▶ We are developing a factor analysis to support outcome hypotheses

ANTIPSYCHOTIC POST WITHDRAWAL HARM

- ▶ Rebound psychosis (Chouinard et al. 2017)
- ▶ Supersensitivity psychosis (Chouinard et al. 2017)
- ▶ Original problems, now un-tranquilized, reassert themselves
- ▶ Additional problems emerge
- ▶ Long-term damage from antipsychotic exposure (Moncrieff 2018)
- ▶ Other damage specific to withdrawal itself?
- ▶ Leads to "relapse", psychotic crisis, hospitalization, re-medication
- ▶ Professionals fail to attribute "relapse" to medication withdrawal

ANTIPSYCHOTIC POST WITHDRAWAL HARM

- ▶ Distinct from antidepressant / benzodiazepine? D2 receptor?
- ▶ GABA receptor adaptation / injury distinct to benzodiazepines?
- ▶ Serotonin receptor adaptation / injury distinct to antidepressants?
- ▶ Benzodiazepine / antidepressant post-withdrawal not associated w/psychosis or acute crisis hospitalization in way antipsychotic withdrawal is?
- ▶ Chronic pain, fatigue, other debilitating symptoms of benzo and SSRI prolonged withdrawal not distinct to antipsychotics?

THREE COMPARISON WITHDRAWAL GROUPS (n=3,423)

- ▶ **A- Off All Meds**
antipsychotics and off all other psych meds
- ▶ **B - Off Just Antipsychotics**
off all antipsychotics and taking any other psych meds
- ▶ **C- Still on Antipsychotics**
includes those also taking other psych meds
(many reduced their antipsychotic dosage)

COMPARISON WITHDRAWAL GROUPS n=3423

group	Freq.	Percent	Cum.
A – Off all meds	1319	38.53	38.53
B – Off just antipsychotics	667	19.49	58.02
C – Still on antipsychotics	1437	41.98	100.00
Total	3423	100.00	

Withdrew from
antipsychotics

SELECTED FINDINGS

- ▶ Overall, off all meds group respondents was widely represented in survey
- ▶ Half of respondents had taken antipsychotics for at least 5 years.
- ▶ 705 respondents were on antipsychotics 20 years or more; 39.46% of those came off all antipsychotics (group A+B)
- ▶ No correlation between education level and group outcome (.02 n=3279)
- ▶ No correlation between employment and group cohort outcome (.05 n=3378)

LONGER ON ANTIPSYCHOTICS WAS WIDELY CORRELATED WITH GREATER DIFFICULTIES AND WITHDRAWAL OUTCOME GROUPS

- ▶ Longer time on antipsychotics correlated with more lasting negative effects (.22 obs=2450)
- ▶ Longer total time on antipsychotics correlated with outcome to remain on medications (.26 obs=3153)
- ▶ Longer time on antipsychotics correlated with withdrawal rated as harder (.24 obs=1486)
- ▶ Longer time on antipsychotics correlated with more severe withdrawal effects (.18 obs=1687)
- ▶ However, longer time on antipsychotics *did not significantly correlate* with greater likelihood of being hospitalized after coming off (.09 obs=1687)

OTHER WITHDRAWAL GROUP OUTCOMES:

- ▶ Age of first hospitalization did not correlate with greater likely to be completely off meds or off antipsychotics (.02 obs=2060)
- ▶ Greater agreement with diagnosis correlated with lesser likelihood to be completely off meds or off antipsychotics (.24 obs=2885)
- ▶ More past attempts to come off only slightly correlated with less likelihood to be completely off meds or off antipsychotics (.11 obs=3030)
- ▶ Exposure to multiple medications simultaneously ("polypharmacy") did not significantly correlate with likelihood to be completely off meds or off antipsychotics (.08 obs=2719)
- ▶ Past inpatient hospitalization correlated with less likelihood to be completely off meds or off antipsychotics (.10 obs=2611)
- ▶ Coping with your symptoms before you took medications correlated with greater likelihood to be completely off meds or off antipsychotics (.10 obs=2611)

"Q18.7 - Would you say you have lasting negative effects from the antipsychotic medication you took?"

n= 2490"

Lasting negative effects from antipsychotics?	outcome group			
	A – Off all meds	B – Off just antipsychotics	C – Still on antipsychotics	Total
no	355	181	242	778
	45.63	23.26	31.11	100.00
	35.32	36.06	24.62	31.24
yes	650	321	741	1712
	37.97	18.75	43.28	100.00
	64.68	63.94	75.38	68.76
Total	1005	502	983	2490
	40.36	20.16	39.48	100.00
	100.00	100.00	100.00	100.00

First row has *frequencies*; second row has *row percentages* and third row has *column percentages*

WHAT DIFFERENCE DID TRYING TO COME OFF MAKE IN YOUR PHYSICAL HEALTH?

What difference did the process of coming off or trying to come off antipsychotics make in your overall physical health?

	Freq.	Percent	Cum.
My physical health is much worse	209	8.46	8.46
My physical health is worse	229	9.27	17.73
My physical health is about the same	613	24.81	42.53
My physical health is better	679	27.48	70.01
My physical health is much better	741	29.99	100.00
Total	2471	100.00	

82.28% reported health the same, better, or much better

57.47% reported health better or much better

DID NEGATIVE WITHDRAWAL EFFECTS FROM ANTIPSYCHOTICS EVER GO AWAY COMPLETELY?

Did withdrawal effects ever go away? When?	Freq.	Percent	Cum.
Yes, in two weeks or less	258	18.03	18.03
No	423	29.56	47.59
Yes, in more than two weeks up to a month	175	12.23	59.82
Yes, in more than a month up to three months	168	11.74	71.56
Yes, in more than 3 months up to six months	111	7.76	79.32
Yes, in six months to a year	130	9.08	88.40
Yes, in more than a year up to two years	82	5.73	94.13
Yes, in more than two years	84	5.87	100.00
Total	1431	100.00	

Note differentiating withdrawal effects and side effects is difficult or impossible; we will attempt to rely on written-in text responses

WHAT DIFFERENCE DID TRYING TO COME OFF MAKE IN YOUR MENTAL HEALTH?

What difference did the process of coming off or trying to come off antipsychotics make in your overall emotional health?

	Freq.	Percent	Cum.
My mental health got much worse	993	37.43	37.43
My mental health got slight worse	369	13.91	51.34
My mental health stayed about the same	295	11.12	62.46
My mental health got slightly improved	538	20.28	82.74
My mental health improved a lot	458	17.26	100.00
Total	2653	100.00	

WITHDRAWAL MEANS CHOOSING OPTIONS AND FEAR YOU WILL REGRET YOUR CHOICE. SO WE ASKED RESPONDENTS...

- ▶ Q18.3 - Are you glad you tried to stop taking antipsychotics? (n=2513)

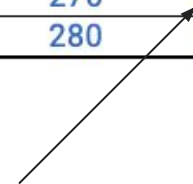
glad tried to stop taking antipsychotics?	Freq.	Percent
no	200	7.96
yes	2313	92.04
Total	2513	100.00

92% OF ALL RESPONDENTS REPLIED "YES" WHEN ASKED "ARE YOU GLAD YOU TRIED TO STOP TAKING ANTIPSYCHOTICS"

- ▶ There was no or very weak correlation between being glad you tried to withdraw and how hard it was (.08 obs=2493)
- ▶ There was no correlation between being glad you tried and being on antipsychotics longer (.07 obs=2467)

OF THOSE WHO CAME OFF ANTIPSYCHOTICS, HOW GLAD THEY TRIED - EVEN IF IT WAS DIFFICULT?

Are you glad tried to stop antipsychotics?	Group A+ B, off all antipsychotics, rate how hard it was to come off							Total
	Extremely easy	Moderately easy	Slightly easy	Neither easy nor difficult	Slightly difficult	Moderately difficult	Extremely difficult	
No	7	4	0	2	3	4	11	31
Yes	217	180	71	158	148	276	399	1449
Total	224	184	71	160	151	280	410	1480



97.32% of
"extremely
difficult to
come off"

ARE RESPONDENTS CURRENTLY EXPERIENCING PSYCHOTIC SYMPTOMS?

Q20.1 - Currently in your life do you ever experience anything doctors might consider as symptoms of psychosis, such as paranoia/suspicion, hearing voices, unusual beliefs, altered states, or severe isolation from other people?

	Freq.	Percent	Cum.
no	1453	57.52	57.52
yes	1073	42.48	100.00
Total	2526	100.00	

HOW DOES EXPERIENCING PSYCHOTIC SYMPTOMS RELATE TO WITHDRAWAL GROUP OUTCOME?

Currently in your life do you ever experience anything doctors might consider as symptoms of psychosis, such as paranoia/suspicion, hearing voices, unusual beliefs, altered states, or severe isolation from other people?	A - Off all meds	B- Off just antipsychotics	C – Still on antipsychotics	Total
no	600	303	544	1447
	41.47	20.94	37.60	100.00
	59.52	59.65	54.29	57.47
yes	408	205	458	1071
	38.10	19.14	42.76	100.00
	40.48	40.35	45.71	42.53
Total	1008	508	1002	2518
	40.03	20.17	39.79	100.00
	100.00	100.00	100.00	100.00

First row has *frequencies*; second row has row percentages and third row has *column percentages*

THANK YOU~~~

- ▶ Contact me will.hall@maastrichtuniversity.nl +1 413 210 2803
- ▶ Share and take the survey! Data collection is ongoing:
www.antipsychoticwithdrawalsurvey.com
- ▶ Join the email list for updates!
<http://bit.ly/SurveyEmailList>
- ▶ Info on withdrawal, including the *Harm Reduction Guide to Coming Off Psychiatric Drugs*, available at www.willhall.net/comingoffmeds

