SHARED DECISION MAKING

EASA Statewide Collaborative
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Craigan Usher, MD
DW Winnicott Professor of Child & Adolescent Psychiatry Education
Oregon Health & Science University

Philosopher Peter Bieri writes that dignity involves freedom to enjoy "our lives as thinking, experiencing and acting beings." Personal agency in psychiatric care is key to restoring and/or maintaining dignity.

SHARED DECISION MAKING

- **Shared Decision Making (SDM) is a collaborative process where the individual works together with their healthcare provider, EASA Team members, and supports (identified family) to make the most informed decision about the treatment or care option that is best for them**

- **It offers a framework intended to support the goals and preserve dignity of individuals**

- **Studies show that SDM can lead to increased levels of satisfaction, quality of life, support around treatments, and a sense that one is respected as an active decision-maker and agent of change in their own lives.**

- **Shared decision making is a feasible intervention during routine first episode psychosis care and does not extend appointment length.**

SHARED DECISION MAKING

- SDM was originally created as a means for talking with people about medication treatment options. This is important because around 35% of individuals with first-episode psychosis (FEP) are likely to benefit from on-going medication treatment in order to promote function and avoid relapse.
- Yet many individuals who enjoy an initial stretch of stability, may be able to taper off of medications.
- Further, while beneficial many, medication treatments cause troubling side-effects.
- SDM is intended to help people navigate, in a very clear manner, the potential benefits and risks of choices that they make, to anticipate difficulties that might arise, and imagine (together with their support system) how to navigate troubles should they arise.
- SDM can be extended to making all kinds of decisions, about housing moves, academics, re-engaging with hobbies, meeting new friends, dating, or other activities

Wunderink L. Personalizing antipsychotic treatment: evidence and thoughts on individualized tailoring of antipsychotic dosage in the treatment of psychotic disorders. Ther Adv Psychopharmacol. 2019;9:2045125319836566.

Stead U, Morant N, Ramon S. Shared decision-making in medication management: development of a training intervention. BJPsych Bull. 2017;41(4):221-227

3 STEPS

SHARED DECISION MAKING

1. CHOICE/TEAM TALK

Articulate that there is a choice to be made and that the EASA participant gets to make that choice. Outline that you will help as a team in the decision-making process.

2. OPTIONS TALK

Exploring the options what might help the person optimally meet their goals. An example of some options might be adding a medication to help with a side-effec, changing to a different medication, or stopping medications. One goal might be symptom-reduction in the service of hanging out with friends.

3. DECISION TALK

Reflecting on the patient's preferences while keeping in mind the advice given by the provider, ultimately rendering a decision on how best to proceed and how the individual might now if the decision they make is fruitful.

SDM DEVELOPMENTAL CONSIDERATIONS

- **Identity development:** adolescence and young adulthood are times where people are questioning who they are, answering if they like who they are, how they interact with the world, and consider what is possible for them.
- Use **non-stigmatizing language** that separate diagnosis from identity. For example, appreciate the difference between “let’s treat your schizophrenia” and “can we address the symptoms your having?”
- **Appreciate** the power of **peer support**
- **Respect social factors** including peer and family influence
- **Be prepared to discuss individual's** preferred levels of **disclosure:** “When I go back to school should I tell people my diagnosis? About going to therapy? That I’m on meds?”
- **Autonomy**
  - During adolescence, individuals seek autonomy/independence from their parents/caregivers.
  - Support this with the both/and appreciation that because many individuals find leaning on their (chosen) family so important during times of vulnerability, they may need others involved in decisions while not having final say.

Special thanks to Shannon Pagdon and Apurva Bhatt for their SAMSHA materials on “Developmentally Appropriate Shared Decision Making” from which this was adapted.

10 PRACTICAL TIPS FOR SDM

1. Never prescribe for a patient or engage in psychotherapy with a client that you cannot remember between sessions. It suggests an insufficient investment in the treatment relationship and your client will feel this. Being curious about the patient's experiences, interests, values, and intersectional identities is exceedingly important as this will inform how they approach decision-making and how you best collaborate.

2. Setting: Meet in quiet, private setting with low stimulation. Make sure all invested parties are invited, particularly EASA Team Members with whom the participant identifies as having a connection.

3. Set-Up: Consider placement of chairs in the office. Try to sit in a circle at eye level with all decision makers.

4. Create a Safe Environment: Ensure needs are met by offering water, tissues, and adjusting seating as needed.

5. Learning Styles: To accommodate learning styles/needs, offer visuals, handouts, and translated materials.

Special thanks to Shannon Pagdon and Apurva Bhatt for their SAMSHA materials on "Developmentally Appropriate Shared Decision Making" from which this was adapted. Appreciation to Andrés Martin and Shashank Joshi for #1.

10 PRACTICAL TIPS FOR SDM

6. Chunk and Check: Use developmentally appropriate language, summarize progress in small chunks, and check for understanding throughout SDM process.

7. Review: Review perspectives; promote respect and mutual understanding.

3. Questions: Invite questions and share resources. Remember no question is a bad question!

9. Follow Through: Act in timely manner on next steps to foster trust. This may mean calling the person you said you would right in front the participant or writing the prescription in front of them.

10. Common Ground: Focus on needs, goals, and common ground when conflict arises. Acknowledge some individuals may prefer a decision that is different from their parent/support person or health care provider.

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ROBIN

This is an interactive case.

INSTRUCTIONS

Individually

- Read through the case
- Feel free to highlight/take notes as you go
- Write down your answers to each question as you go

As a group

- Discuss answers to the case questions

Developmental Hx: Robin was born at 38 weeks, with no prenatal/perinatal complications. She met developmental milestones on time. Her preschool and grade school teachers noted that Robin was very shy and during her 4th grade year she had an 8month stretch of selective mutism.

Past Medical Hx: no hx of seizures, head injuries, severe or recent infections, GI, endocrine, cardiac, pulmonary, or neurological disease

Past surgical Hx: None

Allergies: Amoxicillin (hives)

BACKGROUND INFORMATION

Robin is a 16-year-old 11th grader who lives in an apartment with her mother, father, and their dog, Skippy. Last week she was discharged from an adolescent psychiatry program. She is now attending her first outpatient appointment in a coordinated specialty care (CSC) program. Her head hung low, Robin announces: "the hospital told me I have schizophrenia and bipolar disorder, I feel tired and shaky. My life is through."

HPI

Robin explains that in the month prior to being hospitalized, she had a noetic moment; she felt that angels were speaking to her, encouraging her to give away all of her possessions, which she did by laying them all out in the courtyard in front of her apartment building. For one week, she stayed up most nights, praying and writing. Eventually teachers at school noticed Robin's pressured speech, an exhausted appearance (eyes were red, with dark circles beneath), and how she seemed lost in assignments. This was out of character for Robin, so they directed her to see the school counselor. The guidance counselor called Robin's mother. When she picked up Robin that day, she was sobbing and talking extremely fast. They went to a nearby ER. There Robin acknowledged hearing the voices of angels and demons, feeling as though her "soul was in a tug-of-war." She was soon admitted to an adolescent psychiatry program and started on medication. Robin says that, almost immediately, she felt more calm, but she reports that this soon gave way to a profound sense of being devoid of emotion. She felt she couldn't think, talk, move, take pleasure in anything. To this day she feels empty, lost, unable to do school work, and wonders if life—so devoid of meaning (with her previous sense of purpose being one she now consider delusional) is worth living.

Authored by: Craigan Usher, MD
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

ROBIN

Question 1:
What is on your differential diagnosis? What are the symptoms of the diagnoses you have in mind?

Question 2:
What data/literature can we rely on to inform treatment recommendations about best addressing the needs of teens with the disorder(s) that you have in mind?

Question 3:

- **do we know what is important to Robin?**
- **what tools might help us or what questions might we pose to Robin in order to discover more about her values, wishes, concerns, background understanding?**

PAST PSYCHIATRIC HISTORY

When Robin was 10yo, she visited with a therapist affiliated with her congregation. She did not speak withat that person, but recalls playing a little with dolls in their office. Her mother quit taking her after a few sessions. No history of suicide attempts, self harm behavior, or aggression. No known history of trauma, abuse, or neglect. Recent inpatient hospitalization for psychosis. Olanzapine was started and titrated up to 10mg every night along with lithium now at 450mg BID.

SOCIAL HISTORY

Robin's parents immigrated to the US before she was born. They found the transition to living in the US stressful, but manageable and felt buoyed by the support of their religious community. They both work full-time. They note that Robin has consistently been a great student and enjoyed after school activities. Robin notes that she has not experienced any bullying, physical, sexual, or emotional abuse, but before answering this question did offer "my parents asked me the same thing, and this is what I told them and the people at the hospital."

FAMILY HISTORY

Paternal grandfather was "moody" and episodic stretches without seeing family or friends; alcohol use disorder.

VITALS

BP- 110/80 HR-70 HT- 5' 2" WT-120.4lbs

MENTAL STATUS EXAMINATION

Sullen, eyes downcast, Robin walked quite slowly into the office and plopped down on the chair, not steadying herself well as she dropped into the seat. Her hands were somewhat shaky bilaterally. Her speech is soft, normal in rate and rhythm. Her Affect was restricted and she described her mood as "meh." Her thoughts were linear with no flight of ideas. She denied any AnVH or AVH, thought broadcasting, insertion, paranoia. She endorsed existential dread without SI, thoughts of self-harm or harming others. Insight/Judgment: fair.

LABS

BUN-6mg/dL CRT-0.8mg/dL Li level-1.1 (on discharge)
TSH-2.6 mIU/L

Authored by: Craigan Usher, MD
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

ROBIN'S DIAGNOSIS

Robin thinks she meets criteria for schizoaffective disorder. Is this an accurate diagnosis?

EVALUATING SYMPTOMS: WHAT IS THE BEST DIAGNOSTIC PARADIGM FOR US TO CONSIDER?

DSM-5-TR DIFFERENTIAL DIAGNOSIS

1. **Schizoaffective Disorder-bipolar type (this is what Robin reports hearing at the hospital)**
2. **Bipolar 1 Disorder**
3. **Schizophreniform Disorder/Schizophrenia**
4. **Post-Traumatic Stress Disorder**
5. **Other...**

SCHIZOAFFECTIVE DISORDER: WHAT IS IT?

1. **D**elusions
2. **H**allucinations
3. Disorganized thinking/**S**peech
4. Grossly disorganized Behavior/abnormal motor behavior (catatonia)
5. Negative Symptoms

"DHS BeNS" with symptoms for at least six months +

- **a major mood episode (depression or mania) concurrent with "DHS"**
- **delusions or hallucinations that occur for 2 or more weeks where depressive or manic symptoms are NOT present,**
- **the mood symptoms are present for a majority of the time**
- **symptoms do not stem from drug use or other substances.**

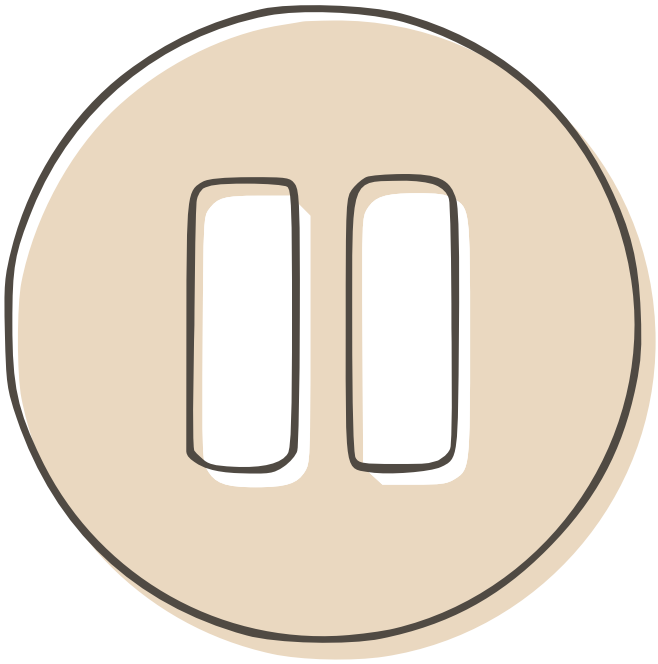
MANIA: WHAT IS A MANIC EPISODE?

A prolonged stretch of persistently elevated mood and energy that entails at least 3 (4 if the mood is only irritable) of the following and lasts at least a week or any amount of time if the person is hospitalized:

- DISTRACTABILITY
- IMPULSIVITY WITH ENGAGEMENT IN ACTIVITY w/ HIGH RISK FOR NEGATIVE CONSEQUENCES
- GRANDIOSITY w/ an inflated sense of self, meaning, purpose, and capabilities
- FLIGHT of IDEAS (one topic leads to the next and the next...)
- ACTIVITATION in terms of new GOALS AND PROJECTS (new projects, many left undone)
- SLEEP DISTURBANCE (needing only a few hours in an out-of-character manner)
- TALKATIVENESS (Rapid speech as if an untied balloon is released and and the air whooshing out)

"DIG FAST"

Authored by: Craigan Usher, MD
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health



PLEASE PAUSE HERE

Please move into your small groups and consider these 3 questions:

1. **Robin would like to know what the optimal therapy and medication treatment for bipolar disorder is. What would you tell her? How can you help inform her decision?**
2. **Robin would like help deciding what to do. What are some questions that you can ask or tools that you can use to find out more about her experiences, interests, values, family culture, and personal identities that might help you better collaborate?**
3. **Related to this, what side-effects did you identify in the history that might be concerning and how might you learn more?**

Once you feel comfortable as a group, turn to the next few pages and read through them (pages 12 - 16) to see how we progressed in the SDM process with Robin.

ROBIN'S TREATMENT OPTIONS

There is some evidence that psychosocial support/therapy is quite helpful in bipolar disorder in teens.

Goldstein TR, Merranko J, Rode N, et al. Dialectical Behavior Therapy for Adolescents With Bipolar Disorder: A Randomized Clinical Trial. JAMA Psychiatry. 2024;81(1):15–24. doi:10.1001/jamapsychiatry.2023.3399

Medication treatment plays an essential role; options include:

1-MONOTHERAPY SECOND-GENERATION "ANTIPSYCHOTIC" (SGA)

2-MONOTHERAPY MOOD STABILIZER

3-COMBINATION (SGA + MOOD STABILIZER)

WITH SGA > MS IN TERMS OF HOSPITALIZATION AND AVOIDING NEED FOR AUGMENTATION IN 12 MO MAINTENANCE

Chen H, Mehta S, Aparasu R, Patel A, Ochoa-Perez M. Comparative effectiveness of monotherapy with mood stabilizers versus second generation (atypical) antipsychotics for the treatment of bipolar disorder in children and adolescents. Pharmacoepidemiol Drug Saf. 2014;23(3):299-308

MANIA RESPONSE (>/= 50% reduction in YMRS)

- **risperidone**
- **olanzapine**
- **aripiprazole**
- **quetiapine**
- **asenapine**
- **lithium**

Vita G, Nöhles VB, Ostuzzi G, et al. Systematic Review and Network Meta-Analysis: Efficacy and Safety of Antipsychotics vs Antiepileptics or Lithium for Acute Mania in Children and Adolescents. J Am Acad Child Adolesc Psychiatry. Published online August 9, 2024.

Authored by: Craigan Usher, MD
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

ROBIN: A CHALLENGE TO SDM, WE DON'T KNOW WHAT IS IMPORTANT TO HER!

Shared Decision Making with Robin...

THE ELEMENTS OF SHARED DECISION-MAKING

- Learn what is important to the participant
- Explicitly invite participants in decision-making
- Present options and information on benefits and risks
- Facilitate deliberation and decision making
- Develop a shared blue print

Before we move on to the 3 step SDM model, we need to find out what's important to Robin!

SDM: 3 Step Model

Choice Talk	Options Talk	Decision Talk
• Making sure participants know that reasonable options exist	• Provide more detailed information on options	• Considering Preferences and deciding what's best

Authored by: Craigan Usher, MD
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

ROBIN

The coordinated specialty care team gathers that Robin's complex intersectional identities, as a suburban public school student, a devout Christian, as a first-generation Korean-American shape her views of mental illness and health in important ways. Thus, they wish to learn more and so turn to the DSM-5 Cultural Formulation Interview.

CFI tools are available online and they provide a structured means of embracing cultural humility and being curious about...

- a person's values, orientations, knowledges, and practices
- their background, experience and the social context of health and unwellness
- the ways they may be influenced by family, friends, and other community members

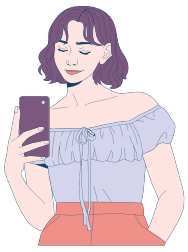
CFI materials consist of the following:

1. Cultural Formulation Interview
2. Cultural Formulation Interview – Informant Version
3. Cultural Formulation Interview – Supplementary Materials
   - Explanatory Model
   - Level of Functioning
   - Social Network
   - Psychosocial Stressors
   - Spirituality, Religion, & More Traditions
   - Cultural Identity
   - Coping & Help-Seeking
   - Patient-Clinician Relationship
   - School-Age Children and Adolescents
   - Older Adults
   - Immigrants and Refugees
   - Caregivers

Semi-structured interviews like the K-SADS and SCID5 help us move from unique person/context and symptoms to a diagnostic construct

DIAGNOSIS

Rich narrative interviews help bring to conscious awareness the many ways that unique experiences, sensibilities, culture, and other factors influence how a diagnosis, symptoms, and treatment impact an individual.



DIAGNOSIS

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ROBIN

Interview

LEARNING MORE ABOUT ROBIN...

USING THE CFI...

Posing questions from the CFI-Supplementary Module on "Spirituality, Religion, and Moral Traditions," you learn from Robin that her family is part of a religious community that emphasizes healthy living. Robin's perception is that her parents' feel that mental health struggles are typically caused by sinful living and that they don't seem to understand why their daughter would be having the kinds of problems she is. For example, they often blamed her paternal grandfather's moody ups-and-downs on alcohol use. They hence adhere to their faith community's strict prohibition against drinking alcohol. They are feeling that if Robin can adopt more healthy practices, then she won't need to be on medication anymore or at least on so many medications. This is of value to her as a result. She would like to be on less meds.

We also learn that Robin notes attends church on weekends, goes to a youth group on Wednesday nights, and prays daily. When she first felt that her mind was racing out of control, like an internet pop up with video/audio that she couldn't shut off, she thought it was because she wasn't praying enough and she was concerned that she was being punished for considering becoming sexually active with her boyfriend. She has lived with side-effects from medicines as she feels it is just punishment.

Finally, we learn that Robin has been the victim of anti-Asian racist bullying; stress about this preceded the onset of manic symptoms.

Authored by: Craigan Usher, MD
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

ROBIN

Side Effect Review

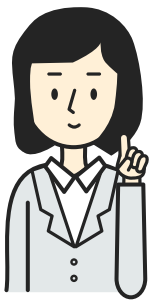
LEARNING MORE ABOUT ROBIN...

USING A COMPREHENSIVE SIDE-EFFECT SCREENING TOOL

Robin notes that she is:

- Tired
- Feels “like a zombie”
- Has had a dry mouth
- Been extremely thirsty
- Goes to the bathroom often
- Is worried about weight gain
- Is anhedonic and concerned that she has no libido

Over the past week:	*Never*	*Once*	*A few times*	*Everyday*	*Level of distress* 1 = not at all 10 = very much
1. I felt sleepy during the day					
2. I felt drugged or like a zombie					
3. I felt dizzy when I stood up and/or have fainted					
4. I have felt my heart beating irregularly or unusually fast					
5. My muscles have been tense or jerky					
6. My hands or arms have been shaky					
7. My legs have felt restless and/or I couldn't sit still					
8. I have been drooling					
9. My movements or walking have been slower than usual					
10. I have had uncontrollable movements of my face or body					
11. My vision has been blurry					
12. My mouth has been dry					
13. I have had difficulty passing urine					
14. I have felt like I am going to be sick or have vomited					
15. I have wet the bed					
16. I have been very thirsty and/or passing urine frequently					
17. The areas around my nipples have been sore and swollen					
18. I have noticed fluid coming from my nipples					
19. I have had problems enjoying sex					
20. **Men only**: I have had problems getting an erection					



For more information on side-effect monitoring, please visit:

- **https://www.phenxtoolkit.org/sub-collections/view/6)**
- **https://www.nice.org.uk/guidance/qs102/chapter/quality-statement-6-monitoring-for-side-effects-of-antipsychotic-medication**

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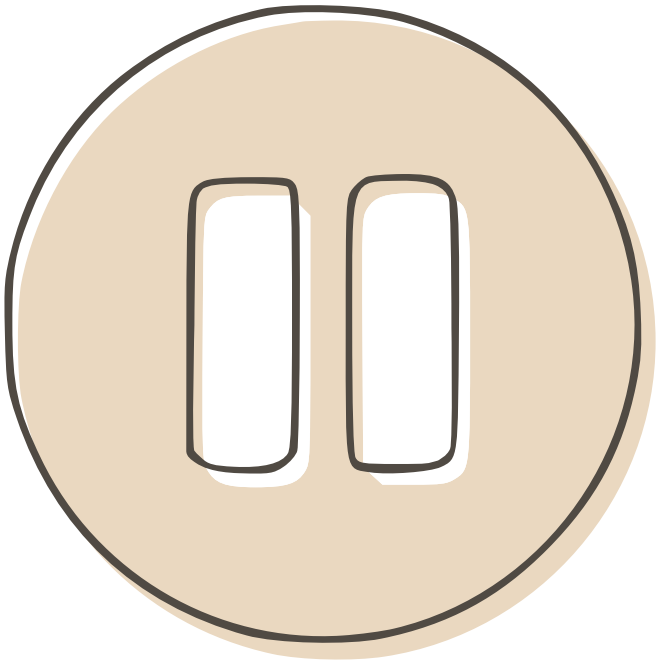
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health



PLEASE PAUSE HERE

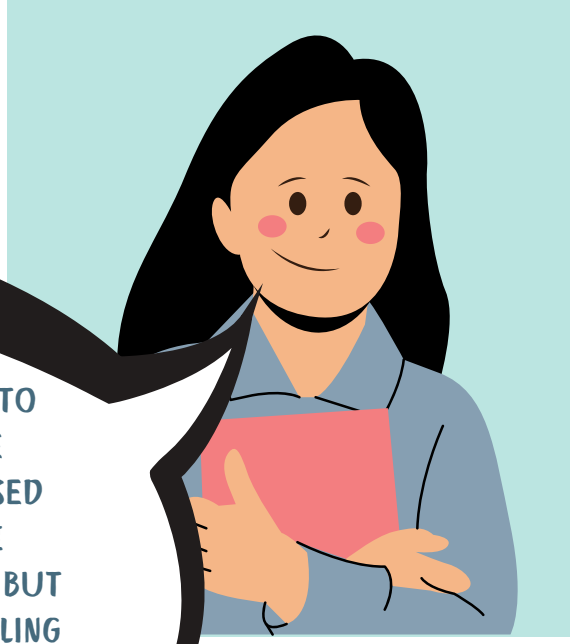
On the next two pages, we'd like you to fill in the blanks,

1) imagining first how Choice Talk, Options Talk, and Decision Talk might go. You may wish to choose two people to role play.

2) picturing how a discussion of the pros and cons of several options might go. If there is no medical provider in your group and you feel more comfortable, then you could consider the question of when she would go back to school...

Once you've done so (reviewing pages 18-20) then you can proceed as a group to how these SDM processes unfolded with Robin.

ROBIN



"THERE IS NO WAY I WANT TO GO BACK TO THE WAY THINGS WERE BEFORE. I GAVE AWAY ALL MY CLOTHES. I AM EMBARRASSED ABOUT HOW I WAS ACTING AT SCHOOL. I DON'T WANT TO GO TO THE HOSPITAL. BUT I CAN'T KEEP GAINING WEIGHT AND FEELING LIKE A ZOMBIE. IF THIS IS WHAT SCHIZOPHRENIA AND BIPOLAR IS, I DON'T KNOW IF I WANT TO LIVE LIKE THIS.

HOW DO YOU IMAGINE THE CONVERSATION ABOUT HOW TO PSYCHOPHARMACOLOGICALLY PROCEED?

Choice Talk	Options Talk	Decision Talk
1)	1)	1)
2)	2)	2)
3)	3)	3)
4)	4)	4)
5)	5)	5)

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EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

ROBIN

On balance...let's determine the best course of action.

IN ROBIN'S BALANCE SHEET, WE ALSO ADDED STOPPING MEDS AND SHE SAID "THAT WOULD BE NICE, BECAUSE I THINK MY PARENTS ARE ASHAMED THAT I'M ON MEDICATIONS. BUT I DON'T WANT TO GO BACK TO THE HOSPITAL AND NEITHER DO THEY. PLUS I'M EMBARASSED ABOUT WHAT HAPPENED AT SCHOOL. SO. NO WAY. I WANT TO STAY ON MEDS FOR NOW."

.

	Switching to another SGA	Sticking with Olanzapine	Lithium Monotherapy
Pros	1. 2. 3.	1. 2. 3.	1. 2. 3.
Cons	1. 2. 3.	1. 2. 3.	1. 2. 3.

Remember: an SGA = second-generation antipsychotic. An example is aripiprazole.

Authored by: Craigan Usher, MD
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

ROBIN

On balance...let's determine the best course of action.

FOR SOME GROUPS, YOU MAY FEEL MORE COMFORTABLE TACKLING A QUESTION LIKE "WHAT ABOUT SCHOOL? I HAVE BEEN OUT SINCE I LEFT THE HOSPITAL."

	Not going back to school	Going tomorrow	Delaying a Few More Weeks
Pros	1. 2. 3.	1. 2. 3.	1. 2. 3.
Cons	1. 2. 3.	1. 2. 3.	1. 2. 3.

Remember: an SGA = second-generation antipsychotic. An example is aripiprazole.

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ROBIN

Evidence Based Treatment for First Episode Psychosis:
HANDOUT 3 - SDM Exercise Answer Sheet

WHAT IS IMPORTANT TO ROBIN, MOM? WHAT ARE THEIR GOALS IN TREATMENT?

Lets talk with Robin and her mom about the medication using SDM principles and help them make a decision.

Choice Talk

You have options AND you get to make the choice. I'll help guide you with my experience and knowledge. I trust we can make a good decision together.

- Keep both meds at the present doses.
- Taper off of olanzapine and keep lithium.
- Taper off of lithium and keep olanzapine
- Lower both medications as you are presently having side-effects
- Taper off of both medicines in favor of a more metabolically favorable SGA

Options Talk

- If we stop your medication, the side effects will likely go away
- We can work to reduce your medication load now that you are out of the acute phase, but holding onto some treatment may be important
- Research shows that about 50% of children, adoelscents and adults will have recurrence of manic symptoms within a year and maintaining treatment with a mood stabilizer (like lithium) or medicine in the same class as olanzapine is recommneded

Decision Talk

- If you're open to it, may we discuss the risks and benefits of several courses of action?
- Is there someone else whom you'd like to be involved in making this decision together? We can involve your mom, your dad, a trusted friend or confidant if you'd like.
- Whatever we do with medications, it is important that we think together about ways you might get more support at school and not have to deal with the racist bullying you've been facing. How do you feel about that?

Authored by: Craigan Usher, MD
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

ROBIN

On balance...let's determine the best course of action!

DECISIONAL BALANCE WORKSHEET CAN ASSIST CHILDREN, YOUNG ADULTS, AND FAMILIES IN DECISION MAKING AND CAN OPEN UP OPPORTUNITIES FOR DIALOGUE WITH PROVIDERS

.

Balancing potential pros and cons...

	Switching to another SGA	Sticking with Olanzapine	Lithium Monotherapy
Pros	1. Less potential weight gain 2. Lower EPS 3. Might work even better!	1. It clearly helped me in the ER and hospital 2. I am aware of how to take it, know that I need a solid 10-12 hrs of sleep on it	1. Like you said, it seems effective in all phases of bipolar disorder in adults 2. Seems to have worked so far 3. Other people on the unit were on it and said it worked.
Cons	1. Might not be effective 2. Could introduce new side-effects 3. Cross tapering will make me nervous	1. Might keep gaining weight and my clothes already don't fit! 2. Might be resopnsible for me feeling so tired 3. Might not be effective if I go way down on it.	1. Blood draws 2. Being thirsty 3. This tremor in my hands

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EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

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On balance...let's determine the best course of action.

FOR SOME GROUPS, YOU MAY FEEL MORE COMFORTABLE TACKLING A QUESTION LIKE "WHAT ABOUT SCHOOL? I HAVE BEEN OUT SINCE I LEFT THE HOSPITAL."

	Not going back to school	Going tomorrow	Delaying a few more days or a week
Pros	1. Would feel less anxious 2. Wouldn't have to face peers or explain what happened 3. Wouldn't have to deal with bullying	1. Rip the Band-Aid off fast! approach has worked for me in the past 2. I might feel good about seeing friends 3. I want to graduate	1. I might be able to let my friends and teachers know I'm coming 2. I could get some backworke done in advance 3. More time to plan things out
Cons	1. Missing friends 2. Missing teachers 3. This is an important part of my identity: being a good students	1. Just thinking about it makes me panic 2. I don't like any of my outfits 3. I don't know if I feel ready	1. I might get more and more used to not going and it might be harder 2. Backwork is accumulating 3. Again, I miss my friends

Authored by: Craigan Usher, MD
EASAC4E, Oregon Health & Science University / Portland State University School of Public Health

THANKS FOR BEING AWESOME EASA TEAM MEMBERS!

We appreciate you participating in the EASA Statewide Collaborative Shared Decision Making Conversation

Please return to the group and provide feedback on this module so that we can modify this material for the future!