Engaging Patients in Informed Decision-Making about Long Acting Injectable Medications

The Care Transitions Network

National Council for Behavioral Health
Montefiore Medical Center
Northwell Health
New York State Office of Mental Health
Netsmart Technologies
Webinar Objectives

• Research shows that patients who are actively involved in clinical decision-making are more likely to adhere to treatment plans and have improved health outcomes and lower costs.

• In Part 4 of this webinar series on long-acting injectable medications (LAIs), learn about messaging and how to engage patients and family members in shared decision-making around this evidence-based treatment.
Outline

• The Balancing Act
• Shared Decision-Making
• Promoting Benefits
• Dispelling Myths
• Integrating Shared Goals
You do not want to be “coercive”...

...but if you are not proactive in dispelling incorrect beliefs about LAIs, patients will never get the chance to make informed choices.
Patients Choose Long Acting Antipsychotic Therapy When Properly Informed

- In a survey of psychiatrists, patient refusal was cited as a primary reason for not prescribing Long Acting Formulations\(^1\)

- In a survey of patients without experience with these agents:
  - 79% cited having never been informed about the option by their psychiatrist\(^2\)
  - 75% of psychiatrists felt that they informed the patient, but only 33% of patients felt informed\(^2\)

Patients Do Choose Long Acting Antipsychotic Therapy When Properly Informed

In a survey of patients with $\geq 3$ months of experience with a long acting formulation:

- Injectable antipsychotics were the preferred formulation$^3$
- 70% of patients felt better supported in their illness by virtue of regular contact with the doctor or nurse who administered their injection$^3$

Talking About Long Acting Formulations

• Start the conversation from the beginning of treatment
• Involve everyone that the client identifies as important to their decision making
• Discuss potential benefits first
• If a patient does not see any benefits to a treatment, it is not for him/her
The Concept of Patient “Activation”

• Activated patients believe that they have important roles to play in self-managing care, collaborating with providers, and maintaining their health.

• They know how to manage their condition and maintain functioning and prevent health declines; and they have the skills and behavioral repertoire to manage their condition, collaborate with their health providers, maintain their health functioning, and access appropriate and high-quality care.

Hibbard et al, Health Services Res 2004 1005-1026
Shared decision making can be an important tool to enhance patient activation
Shared Decision-Making:
Helping the patient make an informed choice

"I'M SORRY. WHAT OTHER OPTIONS ARE THERE?"
Patient Choice

• The need for patient involvement, empowerment, and choice is widely recognized

• Many clinicians may be unaware that their counseling style may stifle a patient's ability to ask questions

• Patients fear challenging the authority of their doctors or being labeled as "difficult"
Shared Decision-Making

• You and your patients make medication choices within the evidence base
• Patients are supported to consider options--the goal is to achieve informed preferences
• The clinician and patient are equal partners--decisions are made together
• Evidence-based medicine is used but is tailored to the individual

Elwyn tell al. 2012
A Basic Fact

• Difficulty with adhering to chronic medical treatments is a human characteristic
• It isn’t just people with psychosis, it is most people
• Despite your excellent relationships with your patients, your patients are human so they can have adherence problems like everyone else
• Help should be the norm, not just given to select people
Non-adherence in the Treatment of Chronic Disorders

- In developed countries, about 50% of patients with chronic diseases adhere to long-term therapy\(^1\)
- Between 33–69% of all medication-related hospital admissions in the U.S. are due to poor medication adherence\(^2\)
- One-third of all prescriptions are never filled\(^3\)
- >50% of filled prescriptions are associated with incorrect administration (not taken as prescribed)\(^3\)

1. WHO Report 2003; Adherence to long-term therapies: evidence for action
We May Need to Look at Ourselves as Contributing to the Problem
Challenges to Shared Decision-Making

• Clinicians should take care to self-reflect on their own beliefs
• Negative assumptions about patient preferences may result in a pessimistic style of delivering information
• Clinicians generally view LAIs as being less acceptable to patients
• In one study, one third of psychiatrists believed patients always prefer oral medications over LAIs (Patel et al. 2009)
Prescriber Issues With Long Acting Formulations

• Knowledge
• Beliefs
• Attitude
• Training
• Experience
• Support
Psychiatrists Cite Multiple Reasons for Not Prescribing Long Acting Formulations

- Sufficient Adherence to Oral
- Patient Refusal
- Antipsychotic Not Available as LAI
- Costs of Drug
- Not Appropriate Option After Relapse
- Poorer Control of Effect Compared to Oral Drug
- High EPS Risk With LAI

EPS=extrapyramidal symptom
Challenges to Shared Decision-Making

• Contrary to these views, patients’ attitudes towards LAIs are frequently positive

• Patients who remain on LAIs either prefer them over oral medications (Walburn et al. 2001) or feel they prevent relapse (Iyer et al. 2013)
Challenges to Shared Decision-Making

• Well meaning clinicians may be unaware that a didactic style of counseling about LAIs may stifle a patient’s ability to ask questions
• Patients may feel they are not being listened to
• Patients may feel they are not given choice in the management
• Patients may be less likely likely to divulge barriers to adherence
• Patients may be more likely to miss appointments and disengage from treatment
Psychoeducation

Customize education...Meet the patient where they are

• Once the patient has engaged with the idea, provide accurate, factual information to help inform their decision

• Start with the patient’s own knowledge about LAIs

• Using this information as a baseline, specific questions can be asked

• Gaps in knowledge or misconceptions can be corrected

• Questions can be encouraged
Psychoeducation

Provide Information...Keep it Simple

• Discuss the pros and cons of each alternative
• Provide this information in an open and honest way
• Give specific information in simple language
• Limit information to a few major points per discussion
Psychoeducation

Reinforce Information

• Repeat and reinforce psychoeducation
• Use recaps, summaries, and handouts
• Regularly check the patient’s understanding using questions
Psychoeducation

- For a patient to make an informed choice about a long acting formulation, information must be:
  - Accessible
  - Understandable
  - Accurate
  - Relevant

- The **therapeutic relationship is the vehicle** through which the clinician helps the patient make an informed choice.
Therapeutic Alliance

• The therapeutic alliance itself can produce desired outcomes
• Patients who perceived a positive therapeutic alliance with their psychiatrist and other staff had improved medication adherence (Sylvia et al. 2013)
• A systematic review found that aspects of the therapeutic relationship such as agreeing on treatment methods and taking a collaborative approach can be particularly influential (Thompson and McCabe 2012)
Techniques to develop a positive Therapeutic Alliance

1) Exhibit affective qualities including warmth, positive regard, lack of tension, and non-verbal expressiveness (DiMatteo 1979)

2) Engage in a communication style based on asking and listening rather than telling

3) Encourage patient participation by answering the patient’s concerns and allowing discussion

4) Establish a collaborative environment focused on mutual understanding and mutual goal setting

5) Utilize psychotherapeutic principles of empathy and respect

6) Allow sufficient time so that the interaction doesn’t feel rushed
Key techniques

• Connect with our patients
• Listen actively
• Understand patients' values, fears, qualities and skills
• Be non-judgmental, collaborative, genuine, flexible, empathic and respectful
• Summarize regularly
• Use Inductive Questioning
• Explore ambivalence

Kemp, et al. 1997. Modified based on material from Maria Arpa, Founder of The Centre for Peaceful Solutions
Long Acting Antipsychotic Formulations: Balancing Pros and Cons for Patients

- Continuous antipsychotic coverage
- No need to remember
- Less conflict over suspected non-adherence
- Confidentiality
- Possibly decreased relapse & hospitalization rates

- More appointments with some agents
- Perceived stigma
- Conversion from oral to LAI
- Fear of pain
- Inflexible dosing / stopping
- Lack of experience
- Negative clinician appraisal

Promoting Benefits
Potential Benefits for Patients

• **No need to remember to take the medication**
• Most people need help taking medications
• It is a hassle to remember to take medications daily
• Long acting formulations means the patient does not have to make an effort to remember
Potential Benefits for Patients

• **No more misunderstandings about dose strengths**

• Many people who take oral medications take the medications at dose strengths different from what is prescribed

• Long acting formulations eliminate the discrepancy between what the patient takes and what the prescriber thinks is being taken
Potential Benefits for Patients

- **Confidentiality**
- Using long acting formulations means that no one sees them taking pills
- This includes young people in their first episode of psychosis who tend to respond well to monotherapy
- This population may have limited privacy due to living in dorms
- Patients with less frequent privacy concerns (e.g. privacy at home but less while on vacation) may also prefer the option of LAIs
Potential Benefits for Patients

• **Less conflict over suspected non-adherence**
• Medication taking is often an area of conflict between patients and their families
• Using long acting formulations can decrease these conflicts
Dispelling Myths
Common Misperceptions About Potential Negative Aspects

Loss of control/cannot stop once I start

• Just like any medication, the patient decides whether they take the medication
• Patients stop long acting formulations just like they do oral medication
• First determine if the medication works
• If it works well, then one can discuss how long to take it
• Encourage the patient to start with one injection and see how it goes
Pain/fear of needles

- It is important to acknowledge that no one likes needles
- **BUT** millions of people get shots around the world
- It is often beneficial to focus the conversation on what supports the patient feels they would need to try an injection
- Example: Often staff going with the patient to the first injection is a simple but powerful support for patients
Common Misperceptions About Potential Negative Aspects

Stigma/Injections are for sicker or court-mandated for treatment patients

• Everyone who is appropriate for daily oral antipsychotic therapy is appropriate for long acting formulations

• This includes first episode psychosis patients and those in recovery on oral medications

• For these groups, the goal of considering long acting formulations is to keep people well

• Only offering long acting formulations after relapse due to non-adherence reinforces false beliefs and stigmatizes them as “only for sicker people”

• Medication non-compliance is a common reality in all aspects of medicine, not only in psychiatry
Common Misperceptions About Potential Negative Aspects

Many agents come in what to patients seem odd dosing strengths

• Dosages for LAIs are often much higher than for the oral formulation.

• Understanding pharmacokinetics can be a challenge for patients and their families; graphics if available often help

• Educate patients and families that efficacy and side effects are much more related to blood levels than amount taken
Pharmacokinetics: Comparing oral to LAI

- Plasma concentrations are often more stable and often peak at lower levels with long acting vs. oral formulations.
- Using visuals like these to compare LAI to oral pharmacokinetic specific to the medication in question can be very useful in dispelling fears about dosage differences.
Addressing Common Negative Perceptions

• Injections are a hassle
  → Depending on the medication you choose, it could be as infrequent as four times a year. You won’t have to remember to take meds every day

• Someone always nags me about taking my pills
  → won’t happen again

• Control over me → control over your illness
Addressing Common Negative Perceptions

• What if I want to stop?
  → You can stop anytime, and if you do, there is less chance of a withdrawal reaction.

• Means I’m sicker
  → it actually means you are more likely to stay well

• Start with one injection and let’s see how it goes
• Why not give it a try!? You might just like it!
Integrate Goals

Put the pieces together with the GAIN Model for Treatment with Long Acting Formulations

“Will these new glasses help him see things my way?”
GAIN Model-Step 1

G= Goal Setting

• Establish Clinical Needs
  • Discover what the patient’s life goals are
  • Talk about current treatment (good/bad) and relationship to goals

• Provide Sensitive Feedback
  • Listen actively, reflecting patient’s experiences
  • Explore delays to goals caused by relapses

• Develop Goal Plan
  • Small, concrete, attainable steps to achieve 1 or 2 goal(s)

• Develop a Plan of Action with the Patient

GAIN Model-Step 2

A = Action Planning

• Explore the advantages and disadvantages of long acting treatment
• Listen actively to the patient’s fears
• Explore links between use of long acting treatments and achieving goals
• Elicit support of family/caregivers
GAIN Model-Step 3

I = Initiate Treatment

• Step by step explanation of treatment process including trial of oral medications first to assess tolerability (if relevant)
• Explain who will administer the LAI and how this is done
• Listen for negative perceptions of injections and put these into an understandable context (eg. Flu shot, vaccinations)
• Elicit feedback from the patient on how treatment is going

GAIN Model-Step 4

N = Nurturing Change

• Explore any side effects or negative experiences and assure the patient that you will address the concerns immediately
• Celebrate positive experiences, reduced symptoms/relapses
• Identify other aspects of the total treatment plan that may help the patient achieve goals (supported employment/education, job training, therapy, etc)
• Reassess goals/repeat

Summary

• Long acting formulations are certainly not the preferred choice by all patients

• However, a substantial number do choose long acting formulations if they are given proper information

• Our job is to make the information available
  o Discuss this option early in treatment, not just when relapse occurs
  o If a patient declines long acting formulations when first presented the option, do not assume that this decision will never change
    --Just like everyone else, patients and their families sometimes change their minds about a treatment
Summary

• Dispel myths with psychoeducation and address common negative preconceptions

• Use the therapeutic alliance to support shared decision making

• Understand the illness from the patient’s point of view

• Use the GAIN model to integrate shared goals
References


References


References


Thank you!

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