

SUPPLEMENTARY TEXT S1

Low-Value Prescribing Focus Group Interview Script (Patients)

Introduction

I would like to thank you for taking the time to join us today. My name is (moderator name) and I will be serving as the facilitator for today's session. I am working with Dr. Thomas Radomski, and my colleague (note taker name) is here to take notes on today's session.

For those of you who have not participated in a focus group before, a focus group is simply a group of people having a discussion about a particular topic.

Today, we will be discussing your perspectives and beliefs about taking medications. *All medications have both benefits and downsides, and we want to learn what makes taking a medication worth it, or valuable, to you.*

We are having this discussion for research purposes. Once we understand your perspectives on what makes taking a medication valuable to you, we will be able to better identify what patients find most valuable in medications, and eventually help providers stop prescribing medications that their patients don't feel are valuable or worthwhile to them.

There are not "right" or "wrong" answers to today's questions. We want to hear as many different perspectives as possible. We would like to hear from everyone, so please speak up, whether you agree or disagree with what is said by others at the table. However, we do ask that everyone be respectful of each other's opinions.

My job as the facilitator is to ask a few specific questions, to explain when things aren't clear, and to keep us roughly on time. I may occasionally summarize or check that I've understood you correctly, and I may at times move the conversation along by changing the topic in order to keep us on-time.

Our discussion will last 60 to 90 minutes and will be audio recorded because it is important to record your exact words. For the sake of the recording, please attempt to speak one at a time and about THIS LOUD. After today, the recording will be transcribed and analyzed for "themes" that emerge in what you say. The transcription and the notes we take during the session will not have any names attached, so the comments you make today will be anonymous. Eventually, we hope to write a report on the information we discover. In the report, we may use verbatim quotes, but we won't use your name or any identifying information that links you to a quote. The original audio files will be destroyed once we have finished analysis.

Your participation today is completely voluntary, and you may stop participating at any time. If you do decide to stop participating after we start talking, we may still use things that you said because it may not be possible to identify your statements and remove them from the transcript. There are no benefits to participating in this research, although some people enjoy sharing their opinions. The only risks to participating are feeling embarrassed discussing sensitive information, or that someone may find out that

you participated in this study although we will do our best to secure your information by storing it on password-protected computers that only study personnel have access to.

As a token of thanks for your participation, you will receive a \$20 pre-paid debit card.

Do you have any questions for me before we get started?

If you have additional questions, you can reach Dr. Radomski at CONTACT INFORMATION.

By staying at the table and participating in the discussion, you consent to participate in this research study.

Questions

I am going to start by asking some questions about what makes taking a medication worth it, or valuable, to you. I understand that what medications you take might be a personal issue, and so you should know you do not have to tell us what medications you are taking in order to answer these questions, though if you are comfortable sharing that information as we talk, it is also fine for you to mention specifics.

In answering these questions, please consider all medications that you take in pill form, but also in the form of injections, intravenous (IV) infusions, creams, inhalers, eye or ear drops, or suppositories (medications given via the rectum). Please also consider any lab or other testing that you must undergo in relation to use of these medications.

First, I'd like to ask: What, if anything, makes you feel like taking a medication is worth it, or, valuable to you?

Now, on the other hand, have you ever taken a medication or medications that you felt were not worth it, or valuable, to you? Why did you feel that they weren't valuable?

Probe for additional elements (not covered in response to the above question):

- 1) Disruptiveness – taking or giving yourself some medications can be inconvenient to take or disruptive to your daily routine or lifestyle. (Examples if necessary: you may have to take a medication at a certain time of the day, under certain circumstances (i.e., with a meal or on an empty stomach), or you may need to perform testing prior to giving yourself a medication)
 - a. What are some ways, if at all, that taking medications or engaging in related testing has disrupted your routine or lifestyle?
 - b. With this in mind, at what point is a medication so disruptive or inconvenient that it is no longer worth it for you take it regularly?
 - c. How, if at all, does how often you have to take or give yourself a medication affect whether it is worth it for you to take?
- 2) Difficulty – taking or giving yourself some medications can be complicated. (Examples if necessary: drawing medicine from a vial to give yourself a single dose or following long instructions written by the doctor)

- a. What are some examples, if you've experienced any, when taking a medication wasn't worth it because it was too difficult to give yourself or the doctor's instructions were too complicated?
 - b. In general, when does taking a medication become too complicated or difficult that it's no longer worth it?
- 3) Side Effects – medications often come with side-effects. (Examples if necessary: some common medication side effects including nausea, fatigue, or dizziness)
- a. Are there any specific side effects you've experienced that have made taking a medication not worth it?
 - b. In general, when do side effects make taking a medication not worth it?
- 4) Discomfort – Some medications are less comfortable to take than others. (Examples if necessary: you may have to give yourself an injection or swallow large pills.)
- a. What are some examples of ways, if at all, in which taking a medication has been uncomfortable for you?
 - b. In general, at what point does the discomfort that the medication causes you make it no longer worthwhile to take?
- 5) Effectiveness – medications often vary in how effective they are in treating the medical condition or addressing the symptom for which they were prescribed. (Examples if necessary: some medications may lower your blood pressure a small amount but not enough. Other medications may only improve your symptoms like pain or nausea a small amount)
- a. In general, how effective does a medication have to be for taking it to be worth it for you?
 - b. Does the medication have to completely eliminate the problem or symptom, or is it worth it if a medication makes the problem or symptoms just somewhat better?
- 6) Cost – Some medications are more expensive than others.
- a. Are there any specific instances you've experienced in which you've been prescribed a medication that you thought cost more than what it was worth?
 - b. Generally speaking, at what point does a medication become too expensive and no longer worth it to take?
- 7) Stigma – sometimes the medications that you take are a signal to others about what medical conditions you may have that you would rather keep private.
- a. What instances, if any, have you experienced, in which taking a medication was no longer worth it because you were concerned that others would know about a medical problem that you have?
- 8) Prescriber – you may receive prescriptions from many different types of healthcare providers, including your primary care doctor, specialists, nurse practitioners, or physician's assistants
- a. To what degree, if at all, does it matter who prescribed you the medication regarding whether you thought taking the medication was worth it or of value to you?

We've covered a lot of ground with these questions, but does anyone have any other thoughts or comments regarding what makes a medication worth it or not worth taking?

Clinical Scenarios

We are now going to switch gears and talk about some scenarios involving medication use that you or others may encounter at the doctor's office. I will provide you with a summary of each scenario, which I will also read aloud. We will then discuss your thoughts about each scenario.

- 1) Mr. A is a 75-year-old man who has heart disease. He tells his doctor that he is more tired than usual. The doctor checks some blood tests, prescribes him a testosterone cream to use every day because it may help reduce his tiredness, and tells the patient to follow up for his physical in a year. (A 30-day supply of testosterone costs \$200.00.) That patient is worried because his pharmacist told him that testosterone might increase his risk of having another heart attack.
 - a. What should Mr. A do?
 - b. We will discuss this a bit further but first, show of hands, based on this information, who would consider it NOT worthwhile or valuable for the patient to take this medication (the testosterone)?
 - c. What else might you want to know to decide if taking this medication was worth it?
 - d. for those who think it is worthwhile to take the testosterone, what might make it not worthwhile?

- 2) Mrs. S is a 65-year-old retired woman who has high cholesterol and diabetes. She has taken the same medicine, called pravastatin, to lower her cholesterol for the past 10 years. She gets a call from a pharmacist who works at her doctor's office telling her that a medicine more effective at lowering her cholesterol and preventing heart attack and strokes, called atorvastatin (Lipitor), is available. He asks her to switch to the new medication. The new medication costs \$10 more a month.
 - a. What should Mrs. S do?
 - b. We will discuss this a bit further but first show of hands, who would consider it NOT worthwhile or valuable for the patient to take this new medication (atorvastatin)?
 - c. For those who think it is worthwhile to switch to the atorvastatin, what might make it not worthwhile?
 - d. What are your thoughts about receiving a call such as this from a pharmacist who works at your doctor's office?

- 3) Mr. R is a 68-year-old newly retired man. He receives a letter in the mail from his new Medicare Advantage insurance plan telling him that a medicine called clopidogrel (Plavix) that his doctor prescribed is no longer necessary and will not be covered by his insurance. He's been taking this medicine since his heart attack 10 years ago. He doesn't understand why his doctor would refill this medicine if he didn't need it.
 - a. What should Mr. R do?
 - b. We will discuss this a bit further but first show of hands, who would consider it NOT worthwhile or valuable for the patient to take this medication (clopidogrel/Plavix)?
 - c. For those who think it is worthwhile to take the clopidogrel (Plavix), what might make it not worthwhile?
 - d. What are your thoughts about receiving a letter like this from your insurance company?

- 4) Mrs. T is a 70 year old woman who takes a medicine once a day called omeprazole (also known as Prilosec) for acid reflux. She has been taking this medication for the past 3 years and feels that

it works well to control the chest discomfort she was experiencing from acid reflux, which was very bothersome to her and prevented her from eating what she wanted. Her doctor recently recommended that she stop the medication or switch to a different medicine that she would need to take twice a day, due to the concern that long-term use of omeprazole may increase her risk of fracturing a bone and may also be associated with the onset of dementia (i.e., Alzheimer's Disease).

- a. What should Mrs. T do?
- b. We will discuss this a bit further but first show of hands, who would consider it NOT worthwhile or valuable for the patient to continue to take the omeprazole?
- c. For those who think it is worthwhile to continue taking the omeprazole, what might make it not worthwhile?

SUPPLEMENTARY TEXT S2

Low-Value Prescribing Focus Group Interview Script (Caregivers)

Introduction

I would like to thank you for taking the time to join us today. My name is (moderator name) and I will be serving as the facilitator for today's session. I am working with Dr. Thomas Radomski, and my colleague (notetaker name) is here to take notes on today's session.

For those of you who have not participated in a focus group before, a focus group is simply a group of people having a discussion about a particular topic.

Today, we will be discussing your perspectives and beliefs about taking medications. *All medications have both benefits and downsides, and we want to learn what you believe makes taking a medication worth it, or valuable*, in the context of your relationship with the individual that you care for.

We are having this discussion for research purposes. Once we understand your perspectives on what makes taking a medication valuable to you, we will be able to better identify what patients find most valuable in medications, and eventually help providers stop prescribing medications that their patients don't feel are valuable or worthwhile to them.

There are not "right" or "wrong" answers to today's questions. We want to hear as many different perspectives as possible. We would like to hear from everyone, so please speak up, whether you agree or disagree with what is said by others at the table. We do ask that everyone be respectful of each other's opinions.

My job as the facilitator is to ask a few specific questions, to explain when things aren't clear, and to keep us roughly on time. I may occasionally summarize or check that I've understood you correctly, and I may at times move the conversation along by changing the topic in order to keep us on-time.

Our discussion will last 60 – 90 minutes and will be audio recorded because it is important to get your exact words. For the sake of the recording, please attempt to speak one at a time and about THIS LOUD. After today, the recording will be transcribed and analyzed for "themes" that emerge in what you say. The transcription and the notes we take during the session will not have any names attached, so the comments you make today will be anonymous. Eventually, we hope to write a report on the information we discover. In the report, we may use verbatim quotes, but we won't use your name or any identifying information that links you to a quote. The original audio files will be destroyed once we have finished analysis.

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you participated in this study although we will do our best to secure your information by storing it on password-protected computers that only study personnel have access to.

As a token of thanks for your participation, you will receive a \$20 pre-paid debit card.
Do you have any questions for me before we get started?

If you have additional questions, you can reach Dr. Radomski at CONTACT INFORMATION.

By staying at the table and participating in the discussion, you consent to participate in this research study.

Questions

To start, I'd like to go around the table so that I can better understand how you help the person you care for take their medications. This could include anything from filling their pill boxes or picking up their medications at the pharmacy, physically give the person you care for their medications, or performing related testing. An example would be checking someone's blood sugar if they have diabetes.

I am going to ask some questions about what makes taking medications worthwhile for the person that you care for. I understand that what medications the person that you care for takes might be a personal issue, and so you should know you do not have to tell us what medications they are taking in order to answer these questions. If you are comfortable sharing that information as we talk, however, it is also fine for you to mention specifics.

In answering these questions, please consider all medications that the person you care for takes in pill form, but also in the form of injections, intravenous (IV) infusions, creams, inhalers, eye or ear drops, or suppositories (medications given via the rectum). Please also consider any lab or other testing related to the use of these medications.

First, I'd like to ask: What, if anything, makes you feel like taking a medication is worth it, or, valuable to the person that you care for?

Now, on the other hand, has the person you care for ever taken a medication or medications that you felt were not worth it, or valuable for them? Why did you feel that they weren't valuable?

Probe for additional elements (not covered in response to the above question):

- 9) Disruptiveness – taking or giving some medications can be inconvenient or disruptive to a person's daily routine or lifestyle. (Examples if necessary: someone may have to take a medication at a certain time of the day, under certain circumstances (i.e., with a meal or on an empty stomach), or you may need to perform testing prior to giving them a medication
 - a. What are some ways, if at all, that taking medications or engaging in related testing has disrupted the routine or lifestyle of the person that you care for?
 - b. With this in mind, at what point is a medication so disruptive or inconvenient that it is no longer worth it for the person you care for to take regularly?

- c. How, if at all, does how often you have to take or give a medication affect whether it is worth it?
- 10) Difficulty – taking or giving some medications can be complicated. (Examples if necessary: drawing medicine from a vial to give someone a single dose or following long instructions written by the doctor)
- a. What are some examples, if you've experienced any, when taking a medication wasn't worth it because it was too difficult to give to the person you care for, or the doctor's instructions were too complicated?
 - b. In general, when does taking or giving a medication become too complicated or difficult that it's no longer worth it?
- 11) Side Effects – medications often come with side-effects. (Examples if necessary: some common medication side effects including nausea, fatigue, or dizziness)
- a. Are there any specific side effects that the person you care for has experienced that have made taking a medication not worth it?
 - b. In general, when do side effects make taking a medication not worth it?
- 12) Discomfort – Some medications are less comfortable to take than others. (Examples if necessary: you may have to give someone an injection or someone may have to swallow large pills)
- a. What are some examples of ways, if at all, in which taking a medication has been uncomfortable for the person that you care for?
 - b. In general, at what point does the discomfort that a medication causes make it no longer worthwhile to take?
- 13) Effectiveness – medications often vary in how effective they are in treating the medical condition or addressing the symptom for which they were prescribed. (Examples if necessary: some medications may lower your blood pressure a small amount but not enough. Other medications may only improve your symptoms like pain or nausea a small amount)
- a. In general, how effective does a medication have to be for taking it to be worth?
 - b. Does the medication have to completely eliminate the problem or symptom, or is it worth it if a medication makes the problem or symptoms just somewhat better?
- 14) Cost – Some medications are more expensive than others.
- a. Are there any specific instances in which the person that you care for was prescribed a medication that you thought cost more than what it was worth?
 - b. Generally speaking, at what point does a medication become too expensive and no longer worth it to take?
- 15) Stigma – sometimes the medications that people take are a signal to others about medical conditions they have that they would rather keep private.
- a. What instances, if any, have you experienced, in which the person you care for was bothered that you or others knew about one of their medical problems because of the medications that they take?
 - b. At what point is taking a medication no longer worth it because someone would know about a medical problem that you have?

- 16) Prescriber – the person that you care for may receive prescriptions from many different types of healthcare providers, including their primary care doctor, specialists, nurse practitioners, or physician’s assistants
- a. Does who prescribed the medication affect how valuable it is? For example, is something prescribed by a specialist more valuable than something prescribed by a nurse practitioner?

Clinical Scenarios

We are now going to switch gears and talk about some scenarios involving medication use that you or others may encounter at the doctor’s office. I will provide you with a summary of each scenario, which I will also read aloud. We will then discuss your thoughts about each scenario.

- 5) Mr. A is a 75-year-old man who has heart disease. He tells his doctor that he is more tired than usual. The doctor checks some blood tests, prescribes him a testosterone cream to use every day because it may help reduce his tiredness, and tells the patient to follow up for his physical in a year. (A 30-day supply of testosterone costs \$200.00.) That patient is worried because his pharmacist told him that testosterone might increase his risk of having another heart attack.
- a. What should Mr. A do?
 - b. We will discuss this a bit further but first, show of hands, based on this information, who would consider it NOT worthwhile or valuable for the patient to take this medication (the testosterone)?
 - c. What else might you want to know to decide if taking this medication was worth it?
 - d. for those who think it is worthwhile to take the testosterone, what might make it not worthwhile?
- 6) Mrs. S is a 65-year-old woman who has high cholesterol and diabetes. She has taken the same medicine, called pravastatin, to lower her cholesterol for the past 10 years. She gets a call from a pharmacist who works at her doctor’s office telling her that a medicine more effective at lowering her cholesterol and preventing heart attack and strokes, called atorvastatin (Lipitor), is available. He asks her to switch to the new medication. The new medication costs \$10 more a month.
- a. What should Mrs. S do?
 - b. We will discuss this a bit further but first show of hands, who would consider it NOT worthwhile or valuable for the patient to take this new medication (atorvastatin)?
 - c. For those who think it is worthwhile to switch to the atorvastatin, what might make it not worthwhile?
 - d. What are your thoughts about receiving a call such as this from a pharmacist who works at your doctor’s office?
- 7) Mr. R is a 68-year-old newly retired man. He receives a letter in the mail from his new Medicare Advantage insurance plan telling him that a medicine called clopidogrel (Plavix) that his doctor prescribed is no longer necessary and will not be covered by his insurance. He’s been taking this medicine since his heart attack 10 years ago. He doesn’t understand why his doctor would refill this medicine if he didn’t need it.
- a. What should Mr. R do?
 - b. We will discuss this a bit further but first show of hands, who would consider it NOT worthwhile or valuable for the patient to take this medication (clopidogrel/Plavix)?

- c. For those who think it is worthwhile to take the clopidogrel (Plavix), what might make it not worthwhile?
 - d. What are your thoughts about receiving a letter like this from your insurance company?
- 8) Mrs. T is a 70-year-old woman who takes a medicine once a day called omeprazole (also known as Prilosec) for acid reflux. She has been taking this medication for the past 3 years and feels that it works well to control the chest discomfort she was experiencing from acid reflux, which was very bothersome to her and prevented her from eating what she wanted. Her doctor recently recommended that she stop the medication or switch to a different medicine that she would need to take twice a day, due to the concern that long-term use of omeprazole may increase her risk of fracturing a bone and may also be associated with the onset of dementia (i.e., Alzheimer's Disease).
- a. What should Mrs. T do?
 - b. We will discuss this a bit further but first show of hands, who would consider it NOT worthwhile or valuable for the patient to continue to take the omeprazole?
 - c. For those who think it is worthwhile to continue taking the omeprazole, what might make it not worthwhile?