

Objective

- To understand patient experiences in their own words, including the benefits and challenges of using ruxolitinib cream

Conclusions

- Overall, most patients with vitiligo express a positive attitude about starting and staying on ruxolitinib cream. Patients reported experiencing minimal side effects
- Although it can take a while to see positive results, patients share that repigmentation can continue to happen over time

Take-Home Message

- Setting appropriate treatment expectations is an important aspect of staying on ruxolitinib cream treatment. This includes length of time to repigmentation, where on the body it is most effective, possible side effects, and what happens when stopping treatment
- Furthermore, educating both patients and healthcare professionals on how to navigate the insurance process and informing patients about available commercial programs may help eligible patients access and remain on therapy

Abbreviations

FDA, US Food and Drug Administration.

Disclosures

SA and AN are employees and shareholders of Incyte Corporation. COB and BS are employees of MyHealthTeam, a Swoop company, who received funding for conducting the social listening on Incyte's behalf.

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Experiences With Ruxolitinib Cream in Patients’ Own Words: A Social Listening Analysis

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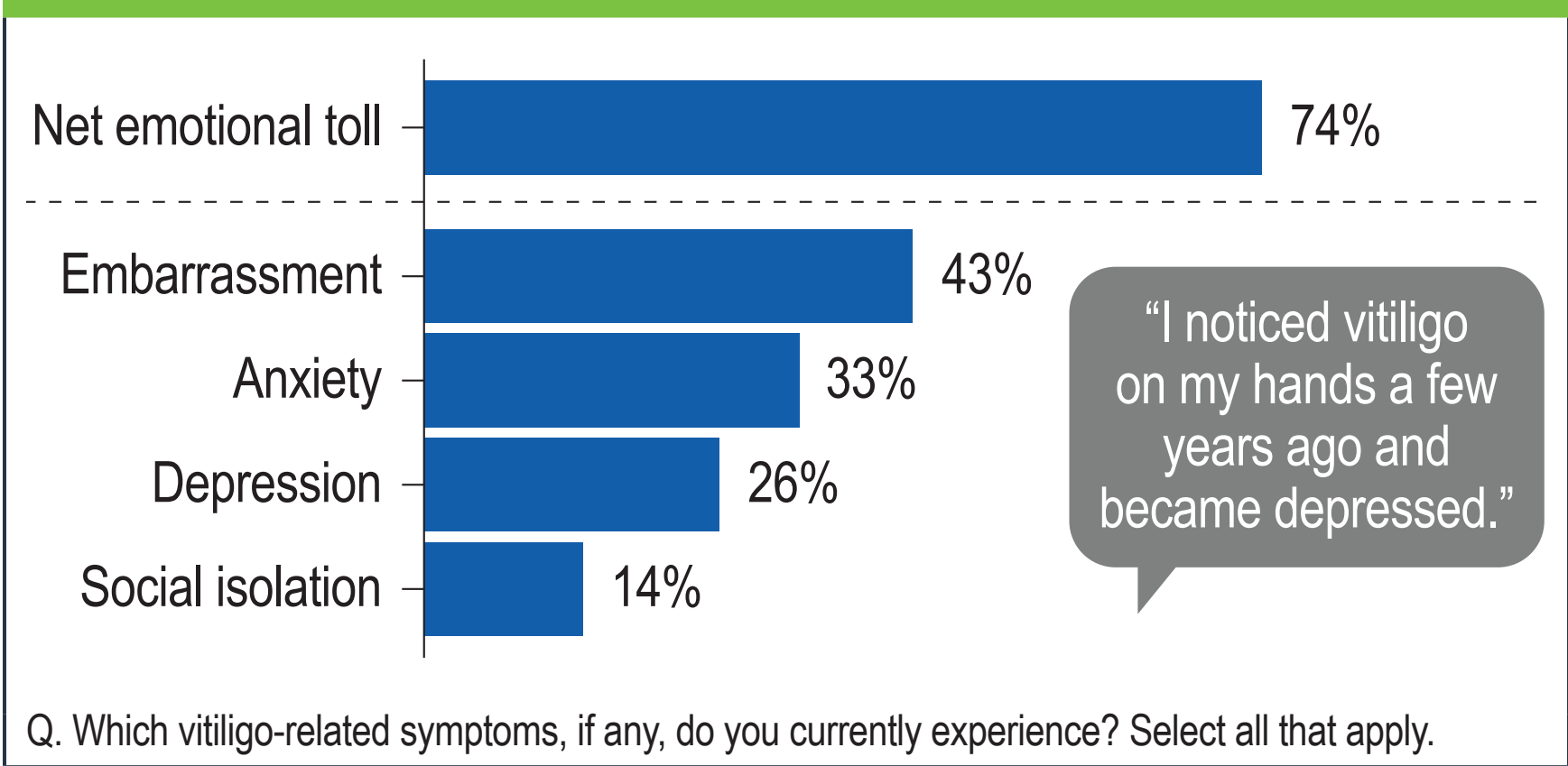
Introduction

- Vitiligo is a chronic, autoimmune skin disease that results in patches of skin depigmentation
- MyVitiligoTeam members organically share their experiences living with and managing vitiligo with one another
- Ruxolitinib cream is the first FDA-approved topical repigmentation treatment for patients with vitiligo
- This study examines recent treatment conversations centered on using ruxolitinib cream (Opzelura®), providing helpful information on patients' hopes, questions, and experiences with this new treatment option for vitiligo repigmentation

Results

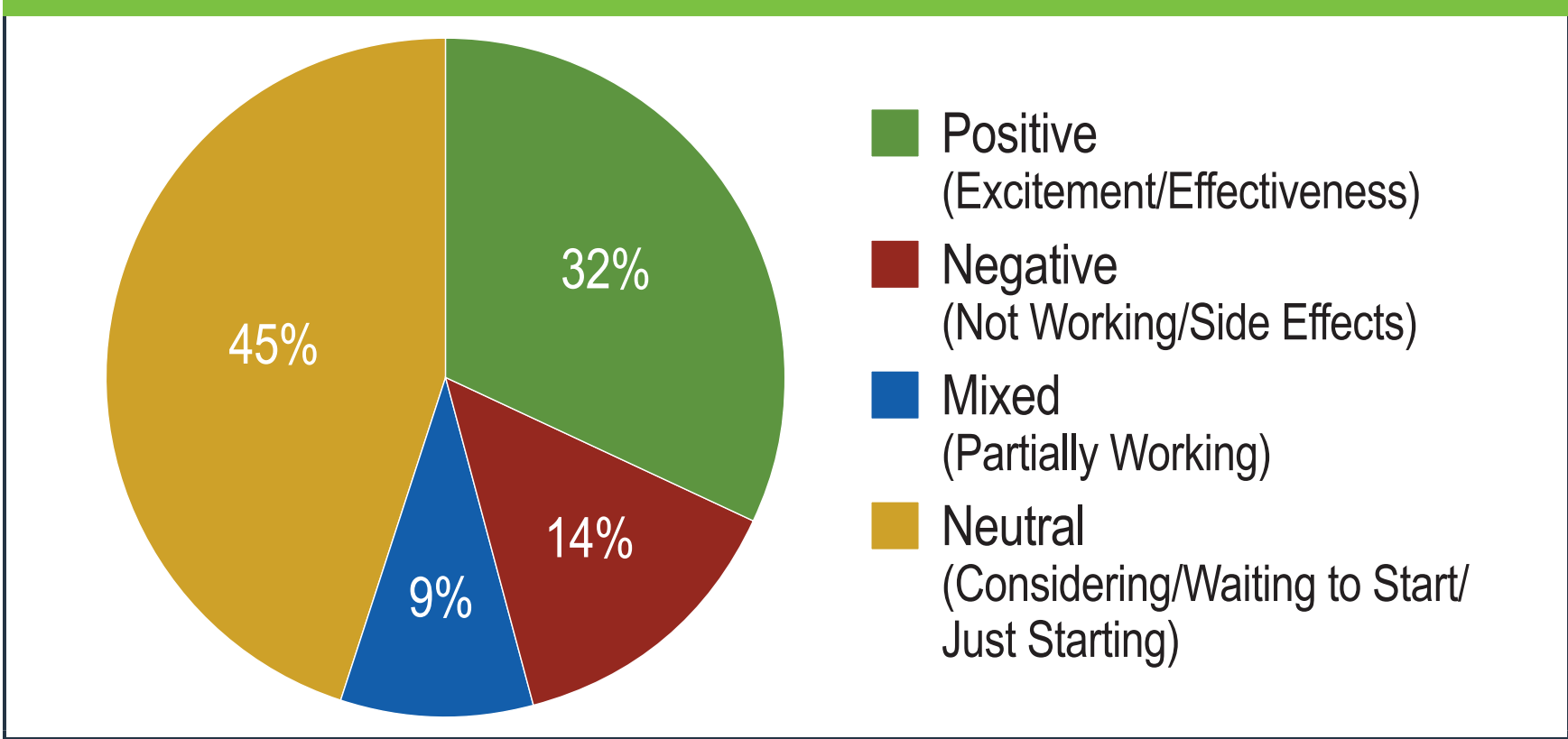
- Previous MyVitiligoTeam survey research found that only 12% of 90 patients with vitiligo using any type of treatment were satisfied with their regimen
 - Most patients were looking for a treatment that would repigment skin (79%), slow progression (52%), or diminish patches (51%)
 - Prior to FDA approval of ruxolitinib cream, 47% of patients who stopped seeing a healthcare professional to treat their vitiligo were told that nothing could be done to repigment the skin
- Based on this social listening research, at least 81/168 members of MyVitiligoTeam had started to use ruxolitinib cream once available
 - An additional 13 who had wanted to try ruxolitinib cream faced insurance or cost hurdles and were unable to start treatment
 - In fact, some were told by their insurer that vitiligo is cosmetic in nature, which is inconsistent with the autoimmune nature of the disease, associated comorbidities, and the emotional toll of vitiligo on patients (Figure 1)

Figure 1. Emotional Toll of Vitiligo Based on Survey Results (N=90)



- Overall, the sentiment of 252 unique conversations related to ruxolitinib cream trended neutral (45%) to positive (32%). This included neutral discussions about getting ready to start treatment and positive discussions about effectiveness (Figure 2)

Figure 2. Sentiment of 252 Unique Organic Ruxolitinib Cream Discussions



Methods

- A passive methodology of social listening was undertaken by analyzing organic discussions about ruxolitinib cream among 168 unique members of MyVitiligoTeam posted from January 2022 to August 2024
 - All organic discussions were anonymized, and no patient-identifying information was shared
- Additionally, results from a 2022 survey among 90 members of MyVitiligoTeam are included to provide the patient's perspective prior to FDA approval of ruxolitinib cream on July 19, 2022

- Ruxolitinib cream treatment effectiveness varied among 81 patients, but twice as many reported positive outcomes (n=31) than negative outcomes (n=15); the remainder were either just starting on treatment or patiently waiting to see results
 - Negative comments mainly stem from a desire for education, including expectations regarding time to repigmentation, prognosis based on body regions, and a better understanding of the risks/side effects
- Results ranged from quick results when applying ruxolitinib cream to specific body parts, particularly the face, to patiently waiting for repigmentation. Some patients started by applying ruxolitinib cream to limited areas of the body, focusing on areas that are most bothersome (Table 1)

Table 1. Examples of Organic Conversations About Ruxolitinib Cream Effectiveness

Positive Sentiment	Neutral Sentiment	Negative/Mixed Sentiment
"I got discouraged really fast in past and stopped using the cream. My doctor encouraged me to restart. I started using it again on my face and can really see the difference in 6 months. Repigmentation takes time. I wish I had used it when I had only few spots on my face."	"I started a new journey with my vitiligo this week. My dermatologist started me on Opzelura. Looking forward to a positive outcome."	"I've been using Opzelura for a while but not seeing too much yet. I also do light treatments."
"I have been using Opzelura 2x daily for 12 months with direct sunlight only. I have 100% repigmentation on my face and 75% on my forearms. Legs are next if my arms get to 100%."	"I've been using Opzelura cream since September and haven't seen any results although they say it could take up to six months to notice if it is working."	"I have used Opzelura for nearly 5 months and my hands have shown very little repigmentation in contrast to my face despite getting lots of sun exposure. I think it's because there are few hair follicles on the hands."
"I can't believe this. Tears of joy! FDA has approved Opzelura by Incyte for treatment in vitiligo. This is the first ever FDA approved drug for vitiligo. You heard me right, the first ever. Our community is part of history. 45 years of having vitiligo and we finally have an approved drug."	"I was diagnosed with vitiligo as a child. I have it on my hands, hips, corners of my mouth, parts of my arms, and back. I'm hoping that the areas on my hands, especially, are able to recover some color."	"My dermatologist had me using Opzelura for a month trial. Unfortunately, it didn't work on me."
"I have been using Opzelura for 2.5 months. It worked quickly on my face. I started seeing results after one week of using it."	"How do you feel about Opzelura? Could Opzelura be used on eyelids to re-pigment white eyelashes and where on the eyelids can this be applied?"	"I've tried the Opzelura with no results, so I don't want to continue that because of the side effects."
"I got vitiligo just 5 month ago. I am taking Opzelura treatment and doing laser treatment. Incredible results."	"Has anyone had success using Opzelura for repigmentation? Also, was it difficult to get a prescription?"	"Over a month using Opzelura, nothing happened."

- MyVitiligoTeam members (N=81) reported experiencing minimal side effects (n=8). Only a small number (n=8) stopped treatment, with 7 citing lack of repigmentation. This suggests that patients are interested in a long-term treatment and understand that repigmentation takes time
- The organic discussions highlighted several questions and concerns that patients have about ruxolitinib cream treatment use
 - These included expectations around repigmentation (extent, evenness, where on the body it works best), compatibility with other products (self-tanners, retinol creams, etc.), the possibility of relapse if stopping treatment, and concerns about the long-term use of the treatment given its cost (Figure 3)

Figure 3. Questions Prior to Starting Ruxolitinib Cream

<p>Does it work? How long until I see an impact?</p> <p>"Has anyone tried Opzelura? If so, what has been your result?"</p>	<p>Where can you apply it?</p> <p>"I have vitiligo on my lips, specifically around the top and bottom. Do you know if Opzelura brings back skin color here?"</p>	<p>Can you use it with other products (eg, self-tanners, retinols)?</p> <p>"Can I put Opzelura on my face if I'm using retinol?"</p>	<p>What side effects are being experienced?</p> <p>"I was recently provided with samples of Opzelura for vitiligo. Has anyone tried this medication? Any side effects?"</p>	<p>Do you have to stay on ruxolitinib forever?</p> <p>"Is repigmentation supposed to be permanent or do you need to use Opzelura forever to maintain it?"</p>
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