

660 Good skin, bad sex: the results from an international crowd-source effort on post-isotretinoin syndrome

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Introduction

- Isotretinoin is an oral retinoid used in the treatment of severe acne unresponsive to traditional treatments.
- Following cessation of isotretinoin use, some patients report long-term side effects known as Post-Isotretinoin Syndrome (PIS).
- Symptoms range from sexual dysfunction to cognitive impairment

Objective

This study aims to characterize the demographic, sexual, psychological, and systemic features of individuals reporting PIS through a cross-sectional questionnaire-based analysis.

Methods

Anonymous Qualtrics survey was distributed via online support forums and social media platforms (e.g. X, Reddit, Facebook) targeting individuals over the age of 18 who reported persistent symptoms post Isotretinoin usage.

Results

- 144 respondents** met eligibility criteria (101 male, 43 female)
- Average age** of start of isotretinoin use was **20.7** (7.4)
- Race:** Asian (5.6%), Black (4.7%), Hispanic/Latino (3.7%), Middle Eastern or North African (3.7%), White (82.2%) Mixed race (5.6%)
- Countries:** United States (40.4%), Canada (8.8%), Mexico (0.9%), Europe (28.9%), Other (19.1%)
- Prior knowledge** of sexual side effects: **No (93%)**, Yes (3.5%), do not recall (3.5%)

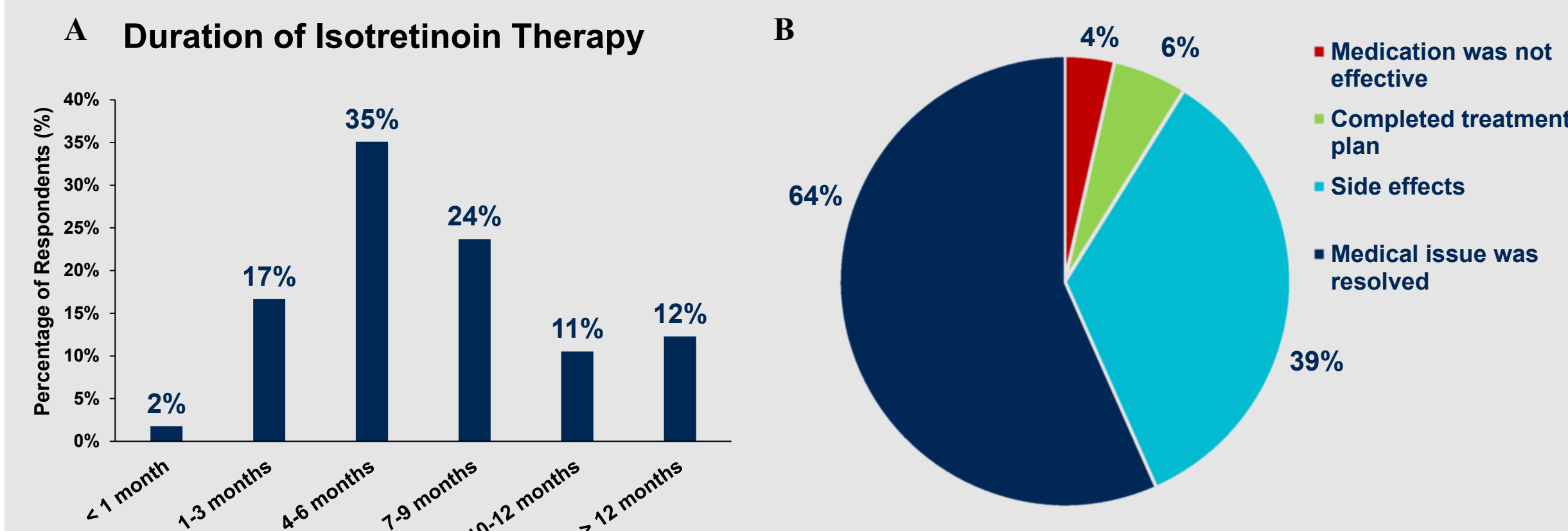


Figure 1: Duration of Isotretinoin therapy varied greatly amongst respondents, with the primary reason for discontinuation being medical issue was resolved. Study participants were asked how long they used Isotretinoin for (A) and what the primary reason for discontinuation of the Isotretinoin therapy was (B).

Table 1: Study participants reported non-sexual symptoms believed to be related to Isotretinoin. *Other symptoms included: Hair changes (loss, dry more body hair), dry mouth/eyes/lips, rapid aging, fatigue, headaches, muscle pain/weakness, pain, voice changes, osteoporosis, food/alcohol intolerance, hearing issues, neuropathy.

Non-sexual Symptoms	N = 104
Cognitive impairment	64 (61.5%)
Mood changes	59 (56.7%)
Skin changes	51 (49.0%)
Joint pain	48 (46.2%)
Loss of/reduction in previous hobbies/interests	43 (41.4%)
Bladder changes	19 (18.3%)
Bowel changes	40 (38.5%)
Visual changes	44 (42.3%)
Difficulty getting pregnant or fertility issues	7 (6.7%)
Other symptoms*	30 (28.8%)
No other symptoms	14 (13.5%)

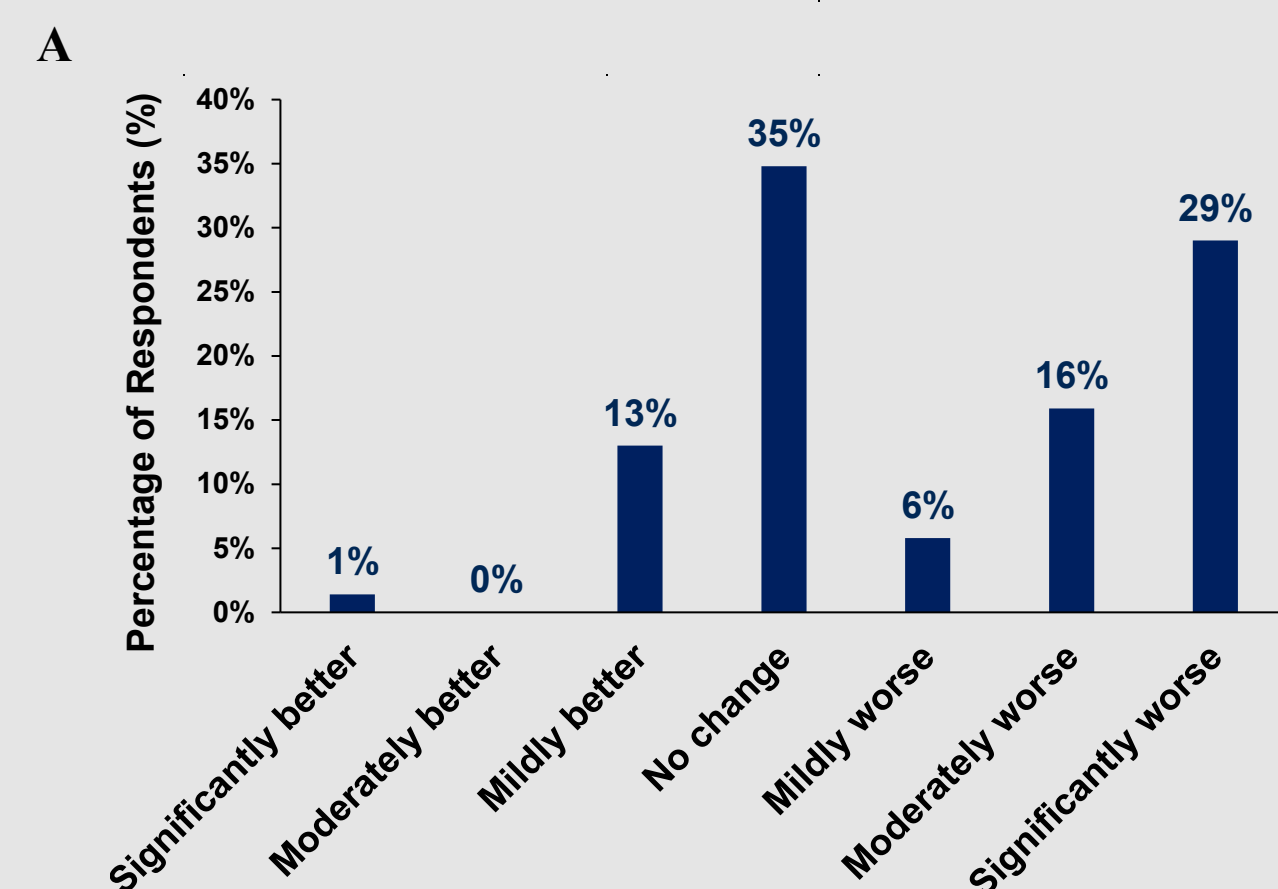


Figure 2: Following discontinuation of Isotretinoin therapy, majority of respondents experienced no change or a worsening of their symptoms.

Study participants were asked how their sexual symptoms change during the therapy and after discontinuation. (A) The majority of patients sought care from a medical professional following discontinuation of Isotretinoin therapy. (B)

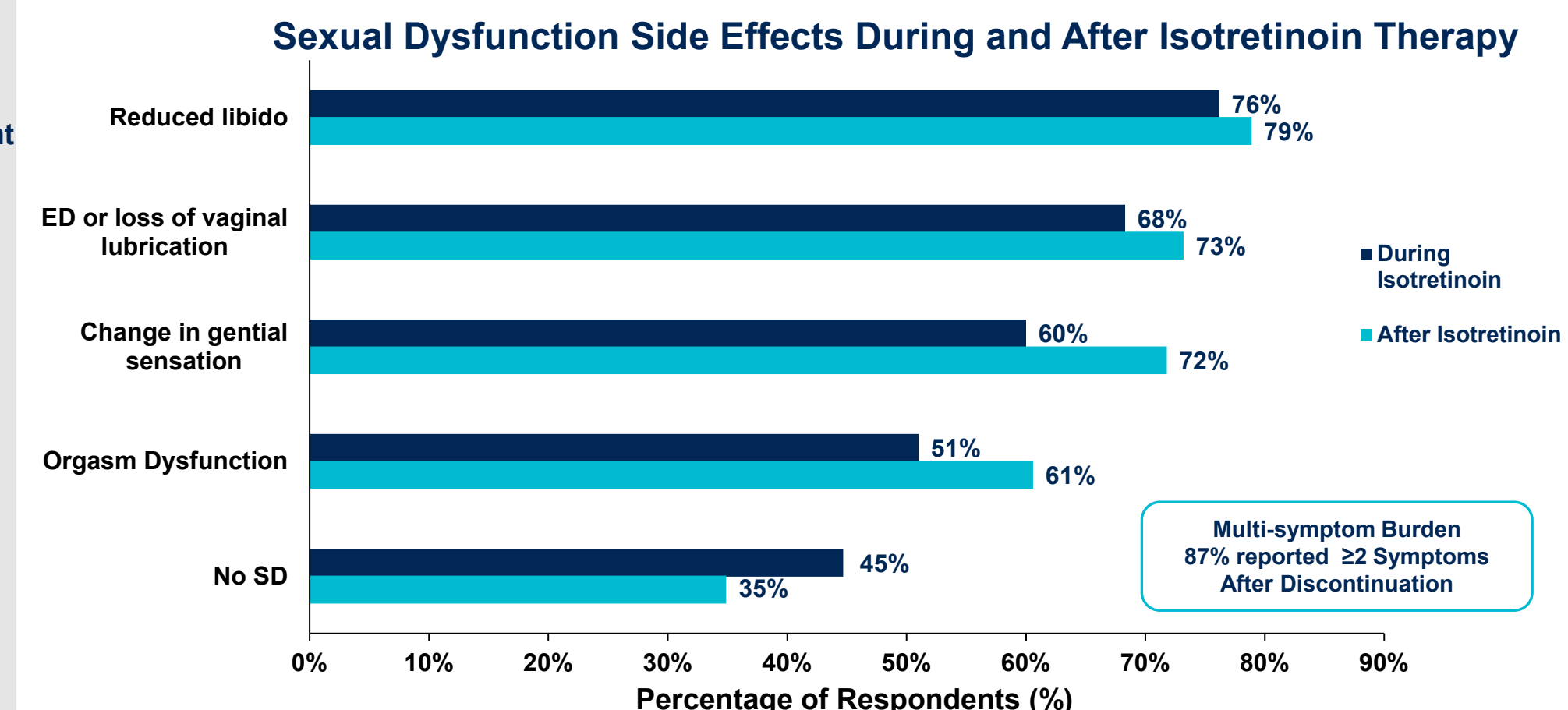
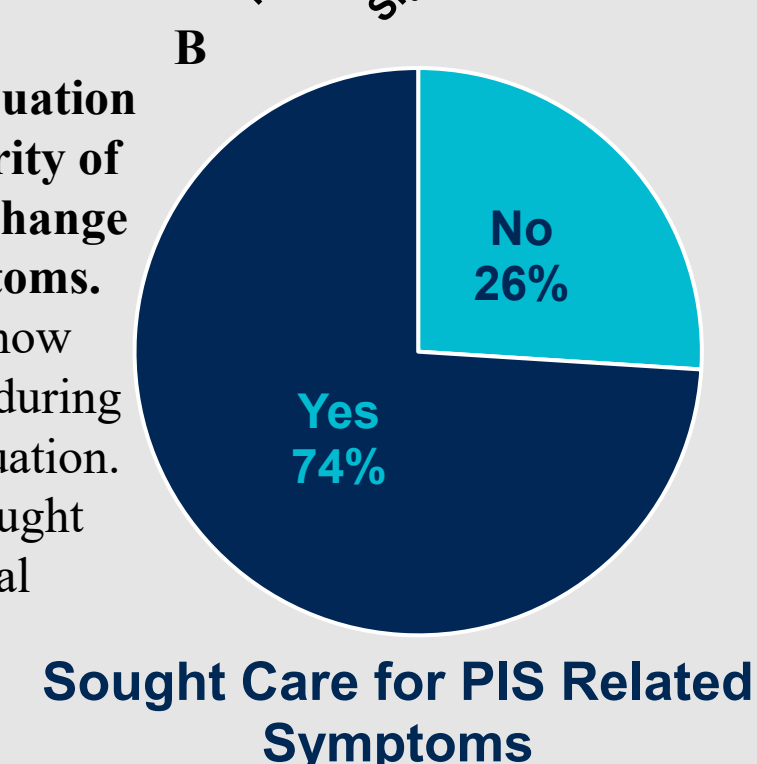


Figure 3: Sexual side effects increased following discontinuation of Isotretinoin therapy. Study participants were asked if they experienced any side effects related to sexual dysfunction, and what type of sexual dysfunction either during Isotretinoin therapy or after discontinuation of Isotretinoin therapy.

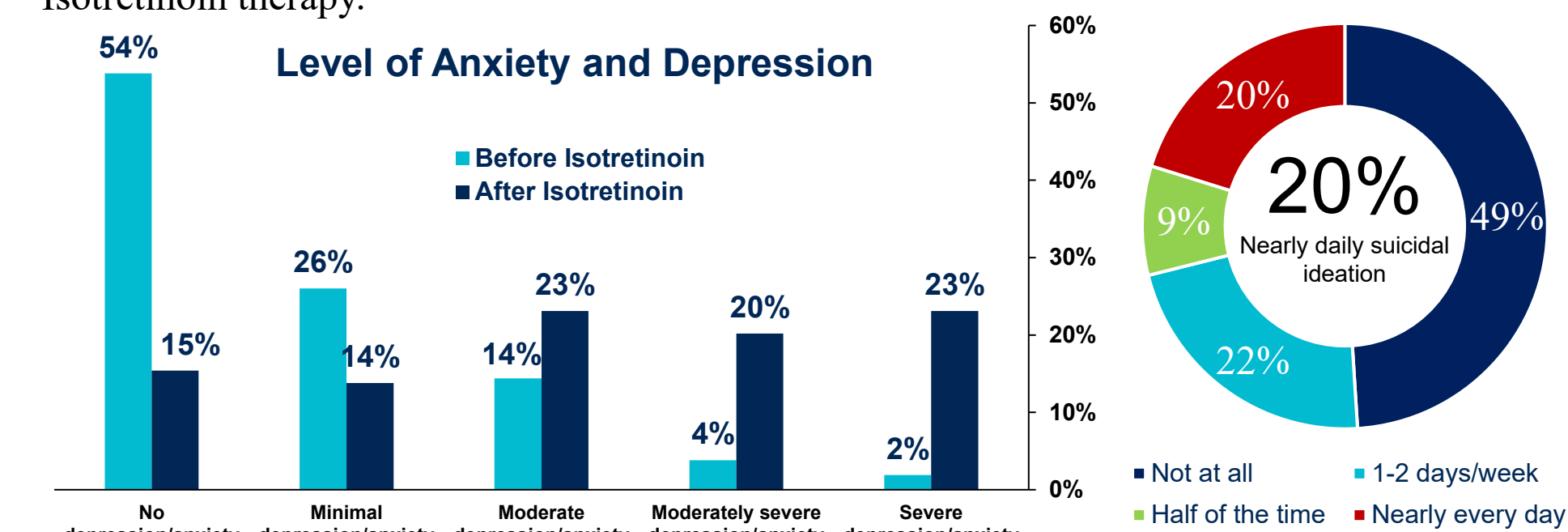


Figure 4: Anxiety and depression both increased following Isotretinoin therapy. Study participants were asked to rank their mental health before and after Isotretinoin therapy (A). Participants were also asked if they had thoughts of hurting themselves or having the feeling they would be better off dead (B).

Conclusion

Individuals living with PIS report significant, multi-system symptoms and decreased mental health following discontinuation of Isotretinoin. Informed discussions regarding potential sexual side effects of Isotretinoin remain low, likely reflecting low awareness from healthcare providers. Moreover, evidence-based approaches for treating this population remain to be elucidated as further research is needed to better understand and support this population.