Barriers and Facilitators of Clinical Research Participation among Racial and Ethnic Minoritized Adults with Psoriasis

By Kelly Su
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Our Team

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Psoriasis Epidemiology

● Common, chronic skin disease affecting ~3% of the U.S. population
● 0.4-2.3% have undiagnosed psoriasis
● Typical onset in 20s to 30s

Psoriasis Epidemiology

- Can affect any part of the skin
- Waxes and wanes over years
- The cause isn’t fully understood
- Genetics and environmental factors
- Associated with comorbidities
Psoriasis Treatment Strategy

Topical therapy

Ultraviolet light therapy
Oral medications
Biologics
## Prevalence and Severity of Diagnosed Psoriasis Differ by Race/Ethnicity

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Prevalence¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>2-4%</td>
</tr>
<tr>
<td>Black²</td>
<td>1.3-1.9%</td>
</tr>
<tr>
<td>Hispanic³</td>
<td>1.6-1.9%</td>
</tr>
<tr>
<td>Asian³</td>
<td>2.5%</td>
</tr>
<tr>
<td>Other</td>
<td>1.4%</td>
</tr>
</tbody>
</table>

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# Impact of Psoriasis on Quality of Life

<table>
<thead>
<tr>
<th>Condition</th>
<th>Mental Functioning</th>
<th>Physical Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthy adults</td>
<td>53.43</td>
<td>Healthy adults</td>
</tr>
<tr>
<td>Diabetes type 2</td>
<td>51.90</td>
<td>Depression</td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>51.67</td>
<td>Arthritis</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>50.43</td>
<td>Myocardial infarction</td>
</tr>
<tr>
<td>Psoriasis</td>
<td><strong>45.69</strong></td>
<td>Chronic lung disease</td>
</tr>
<tr>
<td>Chronic lung disease</td>
<td>44.47</td>
<td>Diabetes type 2</td>
</tr>
<tr>
<td>Depression</td>
<td>34.84</td>
<td>Congestive heart failure</td>
</tr>
</tbody>
</table>

# Quality of Life Impact of Psoriasis Differs by Race/Ethnicity

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Dermatology Life Quality Index Mean (SD)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>White (N=8,338)</td>
<td>5.6 (6.1)</td>
</tr>
<tr>
<td>Black (N=404)</td>
<td>8.3 (7.6)</td>
</tr>
<tr>
<td>Asian (N=436)</td>
<td>7.9 (7.4)</td>
</tr>
<tr>
<td>Hispanic (N=668)</td>
<td>9.0 (7.6)</td>
</tr>
</tbody>
</table>

Reference = White

*Adjusted for age, sex, education, employment, region, income, marital status, insurance, smoking, alcohol use, medical history, psoriasis history (type, duration, treatment), body mass index, psoriasis severity (body surface area, Physician Global Assessment), Hospital Anxiety and Depression Scale.
Participant Diversity is Essential to Clinical Research Studies

Research Question

What are the patient-identified barriers to and facilitators of participation in clinical research studies among Asian, Black, and Hispanic/Latinx adults with psoriasis?
Methods

- Individual semi-structured interviews of Asian, Black, and Hispanic/Latinx adults
- Purposive sampling until we achieved data saturation
- Grounded theory approach and Nvivo software
## Results

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total participants</td>
<td>26</td>
</tr>
<tr>
<td>Age (median, IQR)</td>
<td>48 years (31-63)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9 (34.6%)</td>
</tr>
<tr>
<td>Female</td>
<td>17 (65.4%)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Asian (non-Hispanic)</td>
<td>10 (38.5%)</td>
</tr>
<tr>
<td>Black (non-Hispanic)</td>
<td>8 (30.8%)</td>
</tr>
<tr>
<td>Hispanic (any race)</td>
<td>8 (30.8%)</td>
</tr>
</tbody>
</table>
Barriers to clinical trial participation among minorities with psoriasis

**Logistics**
- Time commitment, scheduling inflexibility, long distance from study location

**Transportation**
- Lack of access to reliable transportation, inability to drive

**Risks & side effects**
- Concerns about risks or side effects of study treatments

**Lack of trust**
- In the scientific process or research team
Logistics/time commitment:
“I live here in Philly, I don't have a car myself, so if it's something that is very out of the way ... after already taking public transportation..., then that's definitely something that I have to consider ... coming to and from is also going to be a time commitment in and of itself. So if it's something that's super far away, I don't know that I would even consider [the study] from a logistical standpoint.”

Risk & side effects:
“If I have a serious adverse reaction to the drug, that would be a concern.”

Lack of trust:
“if the person that is talking with me is not making me feel safe, is not conveying that I'm going to be-- This is how you're going to be taken care of, this is how we're going to take care of you because we are concerned about your safety...”
Facilitators

to clinical trial participation among minorities with psoriasis

**Compensation**
Adequate compensation

**Altruism**
And the ability to help others

**Betterment of treatment**
The desire to find better treatments and improve psoriasis

**Knowledge**
The potential knowledge to be gained about psoriasis
Compensation and betterment of treatment: “Oh, just knowing that it's something that eventually will be available to other patients to help better manage their symptoms. And I think reimbursement and doing these studies is always a positive as well.”

Knowledge: “I know that black and brown people aren't really considered in psoriasis studies... Diversifying your research group will add to the findings that I think will benefit the medicines that may come as an outcome of these studies. I think it's super duper important that we're including different groups of people, especially in this country, we're such a diversified nation.”

Altruism: “I guess wanting to make sure that people that are currently having psoriasis or future generations that could have it are getting the help they need in an efficient way, in a way that actually works and it helps them.”
Conclusion

- Next steps: investigator-identified barriers to and facilitators of recruiting and enrolling Black, Hispanic/Latinx, and Asian patients
- Apply our findings to design future clinical research studies and interventions aimed at increasing participant diversity
Lessons Learned

- Comprehensive insight on qualitative research
  - grounded theory approach, purposive sampling, data saturation, thematic analysis, inter-rater reliability
- Create a codebook and use NVivo software
- Significance of “adequate representation” in clinical trials and data disaggregation in subgroups
- Academic dermatology, balancing clinic and research, and furthering research skills through advanced degrees
Acknowledgements

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Thank you!
Questions?