Dermatology research with the Observational Health Data Sciences and Informatics (OHDSI) network

The Observational Health Data Sciences and Informatics (OHDSI) network enables access to billions of de-identified, standardized health records and built-in analytics software for observational health research. We review dermatology uses of OHDSI. The OHDSI collaborative network established an Observational Medical Outcomes Partnership, a public-private partnership between the FDA, pharmaceutical entities, and healthcare providers. Instrumental to OHDSI is the Common Data Model, which establishes transformation conventions into a single standardized data format, supporting large scale analytics across heterogeneous data partners. Similarly, a standard vocabulary exists, enabling interoperability between systems, facilitating homogeneity and data transparency, and supporting high-quality research. OHDSI studies may be conducted by writing custom code or using built-in software. OHDSI has dramatically enhanced the ease and speed of observational studies. Its scale lends increased power and exposures, diseases, and outcomes. Various applications of OHDSI are represented in the literature, particularly in adverse event reporting, heritability estimation, adherence to treatments, and characterization of prescriptive patterns. Together, these results illustrate the potential of OHDSI in dermatology: its adoption would facilitate examination of treatment patterns that lack best practice guidelines, improve the dermatologic knowledge base, and ultimately, patient outcomes. Bibliometric analysis revealed increasing numbers of dermatology OHDSI studies, which were more likely to report OHDSI use than studies published before the establishment of OHDSI. OHDSI has significantly enhanced the ease and speed of observational studies.

The problem of change scores in dermatology clinical trials

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Change scores are common, but important underlying assumptions, such as stable disease at baseline,均有 outcomes changing linearly with an approximate slope of one, are necessary for use and interpretation. Likewise, transformations like dichotomized endpoints and percentage change from baseline present unique problems. To assess change score use, we queried all 2015-2019 clinical trials from JAMA Dermatology, BJD, IJD, JAAD, and IJEAD, summarized change score use, and evaluated underlying assumptions. Seventy-four trials used pre-post baseline scores, 25 used percentage change baseline, 93 used dichotomized cut points, and 17 used baseline-adjusted scores. We found that change score use varied, with two study-discussed change score options (0.4%). Eighty-two trials used outcomes for patient selection (32.3%). Seven (8.5%) used a post-selection score for baseline and 16 (19.5%) had a run-in time prior to baseline scoring. Twenty-two studies (15.4%) plotted mean outcome values over time and an additional 39 (29.2%) plotted various change scores. Forty-four (38.9%) scores appeared linear, but only 5 (4.40%) had a slope of approximately 1. The FDA often mandates change score outcomes for medication approval. Accordingly, industry-funded trials were more likely to use change scores (OR from logistic regression=2.90, 95% CI 1.75-4.82), especially when compared to all other racial/ethnic groups. We affirmed that Black MF/SS patients had worse outcomes and demonstrated that Black patients had a higher rate of development of folliculotropism and/or large cell transformation, which are aggressive features that may portend a poor prognosis. Racial/ethnic disparities in prognosis across CL subtypes have not been well elucidated. We present a novel center stratified study of 3 patient examining racial/ethnic variance in prognostic features and survival among all subtypes of CL. Our population was comprised of 10.4% Asian, 8.1% Black, 20.4% Hispanic, 59.7% white, and 1.4% of unknown race/ethnicity. 46.2% female and 53.7% male, and 16 distinct subtypes of CL. We found that Black CL patients had worse overall survival (p<0.0001) when compared to all other racial/ethnic groups. We confirmed that Black MF/SS patients had worse outcomes and demonstrated that this held true regardless of stage (p<0.0001). Additionally, we showed that, in the MF/SS population, Black patients had a higher rate of development of folliculotropism and/or large cell transformation, which are aggressive features that may portend a poor prognosis. Racial/ethnic disparities in CL have a tangible impact on the lives of Black patients with increased morbidity and mortality. Further studies are required to investigate the mechanisms, whether genetic and/or extrinsic, behind these inequities as to better guide treatment and ancillary care for the improvement of outcomes for the Black CL population.

Significant disparities in prognosis and survival in Black cutaneous lymphoma patients emphasize the need for more focused study and care

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Cutaneous lymphomas (CLs) are a rare type of non-Hodgkin lymphoma that consist of a diverse group of B- and T-cell subtypes, with the most common of which is mycosis fungoides (MF) and Sézary syndrome (SS). While some CL subtypes are indolent, others may be aggressive and associated with decreased survival. Previous studies have shown worse outcomes and poorer survival for Black patients with MF/SS; however, this data is sparse, and racial/ethnic disparities in prognosis across CL subtypes have not been well elucidated. We present a novel center stratified study of 3 patient examining racial/ethnic variance in prognostic features and survival among all subtypes of CL. Our population was comprised of 10.4% Asian, 8.1% Black, 20.4% Hispanic, 59.7% white, and 1.4% of unknown race/ethnicity. 46.2% female and 53.7% male, and 16 distinct subtypes of CL. We found that Black CL patients had worse overall survival (p<0.0001) when compared to all other racial/ethnic groups. We confirmed that Black MF/SS patients had worse outcomes and demonstrated that this held true regardless of stage (p<0.0001). Additionally, we showed that, in the MF/SS population, Black patients had a higher rate of development of folliculotropism and/or large cell transformation, which are aggressive features that may portend a poor prognosis. Racial/ethnic disparancies in CL have a tangible impact on the lives of Black patients with increased morbidity and mortality. Further studies are required to investigate the mechanisms, whether genetic and/or extrinsic, behind these inequities as to better guide treatment and ancillary care for the improvement of outcomes for the Black CL population.