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USE OF OPIOIDS AND BURDEN OF DISEASE IN PATIENTS (PTS) WITH SICKLE CELL DISEASE (SCD) IN BRAZIL VS THE OVERALL POPULATION OF THE INTERNATIONAL SICKLE CELL WORLD ASSESSMENT SURVEY (SWAY)

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Goals: SCD is a group of inherited blood disorders associated with short- and long-term complications. Acutely painful vaso-occlusive crises (VOCs) are the hallmark of SCD and can lead to hospitalization. SWAY assessed the burden of SCD, the impact of disease on pts'lives and management of SCD. We evaluate geographical variation in pt-reported use of opioids and burden of disease among pts with SCD who participated in SWAY. Materials and methods: SWAY was a cross-sectional survey of pts with SCD and healthcare professionals and was developed by SCD experts, pt advocates and Novartis. Opinions were captured using a 1-7 Likert scale for some questions (a score of 5-7 indicated high satisfaction/impact/agreement). Results: In total, 2145 pts from 16 countries (Bahrain, Brazil, Canada, France, Germany, Ghana, India, Italy, Lebanon, Netherlands, Nigeria, Oman, Panama, Saudi Arabia, UK and USA) were surveyed (3 April-4 October 2019). Mean (SD) age of pts was 25 (13.1) years in the overall population and 23 (14.0) years in Brazil (n = 260). Globally, 53% of pts reported ever having received opioids and 34% reported use of them at the time of the survey. Substantially fewer pts in Brazil reported use of opioids (ever, 37%; at the time of the survey, 20%) than in the overall population. In Brazil, 28% of pts reported \geq 5 days of background pain in a week (ie chronic pain) compared with 23% in the overall population. In Brazil vs the overall population, chronic pain was reported by 38% vs 32% of pts who reported having received opioids and by 22% vs 12% of pts who reported never having taken opioids. Most pts who reported ever taking pain management medication both in the overall population and in Brazil also reported a high level of concern (Likert score 5-7) over the perception of taking it (overall population, 61%; Brazil, 60%). More pts in Brazil vs the overall population reported concern over the side effects of pain management medication (75% vs 69%) and expressed a desire for alternatives to their ongoing pain management medication (78% vs 72%). Discussion: Results from this analysis of SWAY show that self-reported use of opioids was much lower in Brazil than in the overall population, despite the degree of self-reported chronic pain in Brazil being relatively high compared with the overall population. Chronic



pain was more common in pts who reported having taken opioids than in pts who had never taken them, both in Brazil and in the overall population. The low level of opioid use in Brazil may be related to several factors, including pt concern over the side effects of pain management medication, as well as other issues, such as access, cost and levels of disease awareness among HCPs; however, these factors are beyond the scope of this analysis. The difference in sample sizes, as well as possible differences in pt demographics, between Brazil and the overall population should also be noted. Conclusion: Around half of pts who participated in SWAY reported taking opioids at some point during their lives. The proportion in Brazil was much lower than this and did not appear to align with the number of pts in Brazil reporting chronic pain. Funding: Novartis Pharmaceuticals provided sponsorship and was involved in running SWAY.

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VASO-OCCLUSIVE CRISIS IN A 12-MONTH PERIOD: PREVALENCE AMONG BRAZILIAN PATIENTS WITH DIAGNOSIS OF SICKLE CELL DISEASE



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Background and aims: Vaso-occlusive crisis (VOC) is one of the hallmark of sickle cell disease (SCD). It is defined as a multicellular adherence causing a painful vase-occlusion, driving the acute and chronic pain associated with the disease, as well as the complication by end-organ damage. In Brazil, it is estimated that about 30% of SCD patients have at least three VOCs per year. This study aims to determine VOC prevalence among SCD patients in Brazil, as well as to estimate the frequency of crises in a 12-month period. Material and methods: Data were obtained through a multi-country (16 countries) survey of unmatched SCD patients and HCPs developed by international SCD experts, patient advocacy groups and Novartis (The SWAY Survey). The subjects were invited to participate via their healthcare professional or patient association groups. All patients with the diagnosis of SCD were eligible for inclusion and those aged 6 to 11 years old completed the questionnaire with a caregiver/parent/legal guardian. VOC characteristics, such as mean number of crises and management strategies