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Abstract

Objective. The VBF COVID-19 Impact Survey is a new instrument created to measure the medical and psycho-social impact of the COVID-19 pandemic on people with vascular birthmarks, anomalies and/or related syndromes.

The pilot survey is a 26 to 28 item self-report questionnaire designed to measure the impact of the COVID-19 pandemic on children and adults living with vascular birthmarks, anomalies, and/or related syndromes.

Method:
The VBF COVID-19 Survey was created, edited, and reviewed by a medical professional. A small focus group of adults living with vascular birthmarks, anomalies, and/or related syndromes and parents of minors living with one were included in the review process.

The instrument was then pilot tested with 11 participants (5 adults living with vascular birthmarks, anomalies, and/or related syndromes and 6 caregivers/loved ones of those living with one).

Inclusion criteria for questions relating to access of care consisted of having sought treatment, scheduled a clinic appointment, and/or received treatment at any time during the COVID-19 pandemic.

The Survey was not restricted to the USA. To validate the Survey, it was initially given to a small focus group of 18 individuals, which returned a completion rate of 83%. Modifications were then made to improve the Survey based on the feedback, and the formal pilot retest with the 11 individuals was then given, which yielded a completion rate of 100%.

Results: The formal pilot study showed promising results that are in line with our research hypotheses of
the COVID-19 pandemic having either a positive, neutral, or negative impact on the vascular birthmark, anomaly, and/or related syndrome community. Six out of the seven participants who sought care during the pandemic reported experiencing skipped, delayed, or cancelled medical care. A third of people who experienced this disrupted care reported a worsening of their vascular birthmark, anomaly, and/or related syndrome as a result. It is possible that this pattern could be dependent on several factors, such as income bracket. Even within this small 11-person group, people found both positive and negative impacts of the pandemic. While one participant experienced adverse effects from having to wear a mask on a long flight, another participant liked their mask because it covered their birthmark.

Conclusion: The results suggest that the VBF COVID-19 Survey may be a reliable instrument for measuring the impact of the COVID-19 Pandemic on adults and/or children living with a vascular birthmark, anomaly, and/or related syndrome.

Recommendation: The survey will be published and promoted on July 11, 2020 on the Vascular Birthmarks Foundation (VBF) website and on various social media outlets with the intention of accumulating 200 or more completed surveys. The survey will remain open from July 11, 2020 until July 31, 2020. Analysis and a final report will be completed for publication by August 14, 2020.