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Data and Demographics
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LEARNING ABOUT WOMEN WITH BLEEDING THROUGH DATA

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THE MOST COMMON SYMPTOMS WERE:

EXCESSIVE MENSTRUAL BLEEDING (35),
MINOR BRUISES (36),
BLEEDING FROM THE NOSE (28),
BLEEDING FOLLOWING SURGERY (29),
BLEEDING FROM THE GUMS (27).

NEARLY 60% OF THESE WOMEN REPORTED
DIFFICULTIES DUE TO BLEEDING SYMPTOMS IN
TAKING CARE OF HOUSEHOLD ACTIVITIES
ATTENDING SCHOOL OR BEING EMPLOYED.

INTRODUCTION AND OBJECTIVES

Women diagnosed as "carrier" of congenital bleeding disorders, are stigmatized in many countries: this prevents an early diagnosis and a proper treatment plan. In many cases the bleeding diseases are not correctly diagnosed because the hemorrhages are erroneously considered normal when they occur in more family members, especially in case of prolonged menstrual bleedings. For all these reasons it is important to find a way to bring women into the open conversation and obtain more data about them. This will allow those who are interested in studying, researching, supporting, and funding a much better understanding of the problems that must be solved.

MATERIALS AND METHODS

MyGirlsBlood, a non-profit organization that provides worldwide awareness for girls and women with bleeding disorders, launched a collection of surveys in 2015. The intent was to neutralize the thinking that we have an insolvable problem by gathering data to begin to understand women's needs, issues and preferences.

SURVEY RESULTS

Seventy-five women with bleeding issues participated from: Pakistan, USA, Macedonia, Australia, Denmark, Nigeria, Philippines, Canada, Kenya, Iran, Chile, Uruguay, Malaysia, Serbia and India.

They reported bleeding disorders of (some have more than one): vWD (29), mild hemophilia (16), Glanzmann's thrombasthenia (2), ITP (2), not yet diagnosed (0), F I (3), F V (6), F VII (1), F VIII (14), F IX (4), F X (1), FXI (3), FXIII (1).

Of the women who reported immediate family members having similar symptoms (only 9 of 59 answering said "None or Not Known").

The most common symptoms were: Excessive menstrual bleeding (35), Minor bruises (36), Bleeding from the nose (28), Bleeding following surgery (29), Bleeding from the gums (27).

Nearly sixty percent of these women reported difficulties due to bleeding symptoms in taking care of household activities attending school or being employed.

CONCLUSIONS

Helping more women get tested and conducting surveys will bring in more data. The data will allow us to integrate with organizations that focus on women's bleeding problems. Together, we will find that these problems may not be so difficult to solve, after all.



MyGirlsBlood

