Writing Assignment 4

In this article it discusses the attitudes of individuals and families who have hemophilia, are carriers of hemophilia, and are affected by hemophilia. Thanks to advances in technology, those affected by genetic disorders, as well as the general population, are able to see predictions on what their children could potentially inherit and how the inheritance of defective genes could affect their lives as well as their families lives.

The methods used in this experiment to determine the attitudes of those affected by hemophilia include three phases. Phase I is Qualitative interviews; Phase II is Hemophilia Screening Survey; and Phase III is Integrated mixed methods that combine the two previous methods. This allowed the researchers to eliminate discrepancies in both phases of the data. In Phase I, a call for participants within this study was placed in the Haemophilia Society's newsletters, website, and social media accounts. This strategy allowed the experimenters to gain a sample of 22 participants (15 females and 7 males). Interviews took place between April 2017 and March 2018. All participants were spread across the UK. After analysis of this qualitative data Phase II was created to gather more data. In Phase II a survey was sent out that was created on the basis of Phase I. Within the survey, participants were asked about their support for two different types of screening programs. One program was to identify carriers of hemophilia before a pregnancy; it was called preconception genetic screening (PCGS). The other program, prenatal genetic screening(PNGS) , was used to identify carriers (and potentially also affected fetuses) during pregnancy.

The results showed that more than fifty-seven percent of the sample supported PCGS and fifty-nine percent of the sample supported PNGS**.** Overall the support for both types of screening came down to a desire to reduce pregnancy terminations and spread awareness on the affects of hemophilia.

In conclusion, families and individuals that are affected by hemophilia are more supportive of screenings when used as a way of preparation to manage life with hemophilia vs terminating a pregnancy that will result in a child having the disease. Many agreed that before or after conception, terminating the pregnancy was not the best way to go because those whose family members are affected or themselves affected have a grasp on achieving the best possible life given their circumstances.

Boardman, F. K., Hale, R., Gohel, R. & Young, P. J. Preventing lives affected by hemophilia: A mixed methods study of the views of adults with hemophilia and their families toward genetic screening. *Mol Genet Genomic Med* **7**, e618 (2019).