The Knowledge and Understanding of Haemoglobinopathies in the West Midlands

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Aims

The aim of this study was to determine the knowledge and understanding of haemoglobinopathies in the West Midlands by recruiting individuals to complete a questionnaire. The West Midlands is a high prevalence area in the United Kingdom for haemoglobinopathies.

Introduction

In 2019/20 there were 12,659 sickle cell patients and 1,744 thalassemia patients in the UK (NHS National Haemoglobinopathy Registry, 2020). This project investigated the knowledge and understanding of haemoglobinopathies in the West Midlands, which has a high prevalence for these conditions. This is due to a diverse population with 16.5% of the population being of Black, Asian and minority ethnic backgrounds (Office for National Statistics, 2018). As a result, there are national screening programmes for these conditions. This study aimed to determine perception and understanding of these conditions.

There are two screening programmes in the UK, antenatal and newborn screening. Antenatal screening is carried out at 10 weeks gestation, where blood samples are taken and analysed and a family origin questionnaire is completed (NHS Sickle Cell and Thalassaemia Screening Program, 2017a). Newborn screening is carried out at 5-8 days old, where a heel prick sample is analysed (NHS Sickle Cell and Thalassaemia Screening Program, 2017b).

Method

Participants were recruited during February 2021, from the Institute of Education at a West Midlands University and consent was obtained. Ethical approval was obtained from Faculty of Science and Engineering and Faculty of Education, Health and Wellbeing. Upon receiving the consent form all participants were allocated a number to anonymise their responses. A questionnaire was sent to all consented participants. This was designed using Jisc Online Surveys and contained 15 questions made up of multiple choice and free text responses, collecting data on their demographic and their knowledge and understanding of haemoglobinopathies.

Results

There were 11 participants involved in this study, figure 1 shows a population pyramid for the study participants, 7 females (64%) and 4 males (36%). The questionnaire contained multiple questions to assess the participants' knowledge of haemoglobinopathies. Figure 2 shows the results from one of the knowledge questions, only 3 participants (27%) correctly identified that haemoglobinopathies were a hereditary disease. The final questions were used to assess participant understanding of haemoglobinopathies, by getting participants' opinions on testing for haemoglobinopathies and if their haemoglobinopathy status would be a consideration when starting a family. 82% of participants already had children and therefore were unsure if it would be a consideration as they did not know much about haemoglobinopathies and already had children.

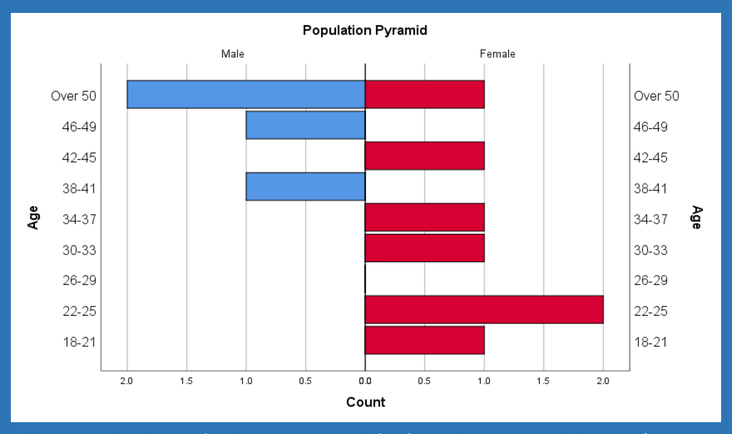

Figure 1: Population pyramid showing participant's age range and gender.

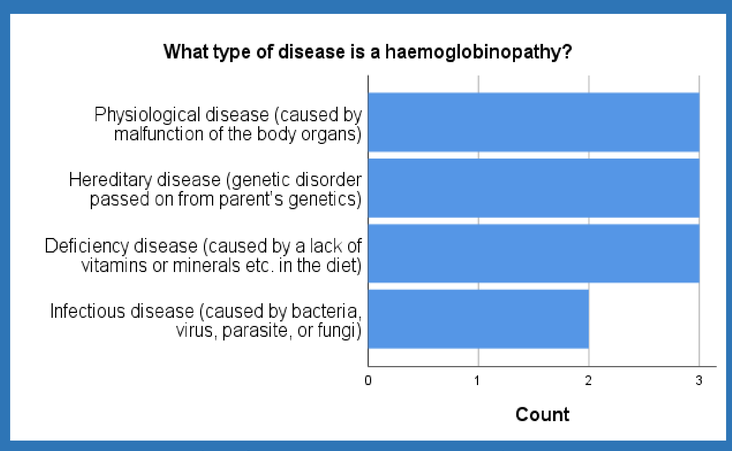

Figure 2: Results for question nine where participants were asked to select the option for which type of disease they thought haemoglobinopathies were.

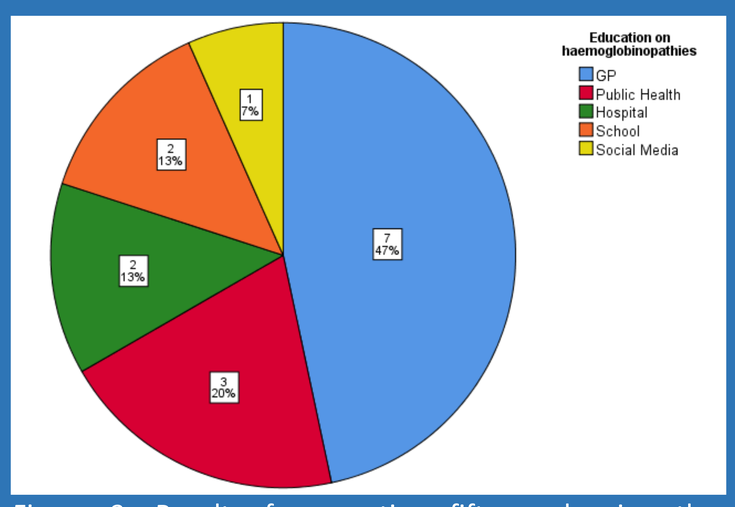

Figure 3: Results for question fifteen showing the different ideas that participants had for how education of genetic conditions such as haemoglobinopathies should be delivered.

The participants were asked if there should be more education on genetic conditions such as haemoglobinopathies and if so how should this be carried out. 82% of participants agreed that more education is needed on these conditions and figure 3 shows how this information could be given. The majority of participants (47%) stated that information should be made available at GP surgeries. Other options identified were Public Health (20%), Hospitals (13%), Schools (13%) and Social Media (7%).

Overall the questionnaire demonstrated a lack of knowledge as only 4 (36%) participants correctly answered 3 out of the 4 knowledge questions and no one correctly answered all 4. A lack of understanding was also shown, but this was most likely due to the participants' lack of knowledge.

Discussion

Gulleroglu, Sarpern and Gokalp (2007); Al Kindi, Al Rujaibi and Al Kendi (2012); Alkhaldi *et al*. (2016); Eissa *et al*. (2018) and Felix *et al*. (2019) used a target population of university students for their questionnaires regarding haemoglobinopathy knowledge. They all found participants lacked knowledge of haemoglobinopathies. As these studies were conducted in the Middle East and Africa, the participants' ethnic background would put them clinically more at risk of haemoglobinopathies. Sickle Cell Disease and Thalassaemia have been linked to protection against malaria, therefore in these areas (Asia, Africa and Southern Europe), genetics that give rise to these conditions or carriers of these conditions are advantageous (Moore, Knight and Blann, 2016). As 91% of participants in this study were White British this does not reflect the ethnic diversity at the University or within the West Midlands. Therefore, future research would involve recruiting a greater number of participants of a Black, Asian and minority ethnic background, as the incidence are higher in these groups. However, due to migration, these conditions are widely distributed in other countries, such as the UK.

Conclusion

This study showed that there was a lack of knowledge and understanding of haemoglobinopathies amongst the participants. As a result greater education should be provided to raise awareness of these conditions. National screening programmes are carried out in the UK and these could be an initial point of education for individuals being screened. This will increase knowledge and understanding of these conditions, as patients should be aware of what they are being screened for and why. Information about haemoglobinopathies, along with other conditions screened for, could be given in a leaflet at the first GP or midwife appointment, to explain the screening process and why it is carried out.

References

Alkhaldi, S.M., Khatatbeh, M.M., Berggren, V.E.M. and Taha, H.A. (2016) 'Knowledge and Attitudes Towards Mandatory Premarital Screening Among University Students North Jordan', *Haemoglobin*, 40(2), pp. 118-124.

Al Kindi, R., Al Rujaibi, S. and Al Kendi, M. (2012) 'Knowledge and attitude of university students towards premarital screening program', *Oman Medical Journal*, 27(4), pp.291-296.

Eissa, M., Patel, A.A., Farag, S., Babiker, N.H., Al-Shahrani, M.S., Al-Nahari, A.M., Al Sahmaa, A. and Al-Shraim, M. (2018) 'Awareness and Attitude of University Students About Screening and Testing for Hemoglobinopathies: Case Study of the Aseer Region, Saudi Arabia', *Hemoglobin*, 42(4), pp.264-268.

Felix, C.E., Chidimma, O.F., Gregory, M.C. and Chinedum, C.F. (2019) 'Assessment of Knowledge and Attitude of Sickle Cell Genetic Screening Among Fresh Undergraduate Students of Ebonyi State University, Abakaliki, Nigera', *Journal of Medical Laboratory Science*, 29(3), pp.8-20.

Gulleroglu, K.S., Sarpern N. and Gokalp, A.S. (2007) 'Public education for the prevention of hemoglobinopathies: a study targeting Kocaeli University students', *Turkish journal of haematology*, 24(4), pp.164-170.

Moore, G., Knight, G. and Blann, A. (2016) '*Fundamentals of Biomedical Science: Haematology'*. Oxford: Oxford University Press

NHS National Haemoglobinopathy Registry (2020) Annual Report 2019/20. Available at: https://nhr.mdsas.com/wp-content/uploads/2021/01/2020_12_NHR_AnnualReport201920_Final.pdf (Accessed: 31 January 2022).

Office for National Statistics (2018) Regional Ethnic Diversity. Available at: https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regional-populations/regional-ethnic-diversity/latest#full-page-history (Accessed: 03 March 2021).

Public Health England (2017a) NHS Sickle Cell and Thalassaemia Screening Program: Handbook for antenatal laboratories. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/656094/Antenatal_Laboratory_Handbook.pdf (Accessed: 26 February 2021).

Public Health England (2017b) NHS Sickle Cell and Thalassaemia Screening Program: Handbook for newborn laboratories. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/585126/NHS_SCT_Handbook_for_Newborn_Laboratories.pdf (Accessed: 26 February 2021).