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EYE CARE IN PEOPLE WHO HAVE DOWN'S SYNDROME: UNDERSTANDING THE PROVISION AND THE IMPACT OF COVID-19

End of study report for the Down's Syndrome Association

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Study background

People with learning disabilities have been estimated to be 10 times more likely to have a serious sight problem than other people. In addition, it has also been suggested that people with learning difficulties often miss out on a number of health services including eye care (SeeAbility, 2016)). The limited current research and data on the experiences and accessibility of eye care for people with learning disabilities means that there is a lack of evidence when suggesting ways to improve access to eye care to this population (Wessex Voices, 2020).

The Wessex Report (Wessex Voices, 2020) aimed to preliminarily investigate this issue surveying 120 adults with learning disabilities across Dorset, Hampshire and the Isle of Wight. Interestingly, despite Down's syndrome (DS) being the most common learning disability, only 10 individuals (out of 120) with DS took part in the survey. Therefore, further research to investigate the provision of eye care in this specific population would be beneficial to health care professionals involved in the care of people with DS, and ultimately to the DS community. Hence, the overarching aim of this study is to provide additional data to understand the eye care provision in people with DS compared to the eye care provision for a control group (i.e. people without Down's syndrome). As a secondary aim, this survey-based study also wants to provide preliminary data on the impact of the COVID-19 pandemic on the eye care of people with and without DS. Although routine eye care has generally resumed world-wide, it can be argued that the previous and current lockdowns and restrictions have impacted eye care services in the same way that most health care services have been impacted seeking to prioritise emergency care and hospital space (Elam et al., 2020).

Summary of methods and procedures

The methods conducted in this study align with those in the Wessex Report (2), and therefore have been proven to be successful for understanding the provision of eye care in people with learning disabilities. The methodology of the study proposed to gather the relevant information and data using an online survey. The online survey as well as the patient information sheets and consent forms were all in an online format. To make our survey more accessible to participants with DS, their survey was converted into Easy Read format.

The online survey, which was developed to be completed anonymously and online using Google forms included questions to help us to understand the following:

1. The participants current eye care (i.e. last eye examination, use of glasses)
2. The experiences of people with and without DS related to eye tests and receiving eye care (i.e. how easy was it to book an appointment, the duration of the eye examination, the communication during the eye examination)
3. Any differences in the participants eye care as a result of the COVID-19 pandemic (i.e. eye test cancellation during the pandemic, eye problems experienced during the pandemic)

Participants with and without DS were recruited via sharing adverts with links to the surveys using social media. The main routes of advertising were the Aston Eye Clinic, Aston Optometry School and the researchers' Facebook and/or Twitter accounts. To support the recruitment of participants with DS, the researchers requested to post the advert and the survey link in the Down's Syndrome Association (DSA),

the Positive About Down's Syndrome (PADS) and the Down's Syndrome Research Foundation UK (DSRF-UK) websites and Twitter accounts.

Study results

The study had a significant success within the DS community and a total of 49 people with DS and 30 people without DS completed the survey. The surveys of four participants with Down's syndrome were excluded from the data analysis as the participants did not meet the age inclusion criteria (two participants were <18 years old) or the surveys were largely incomplete (n=2). Hence, the data analysis included the surveys of 45 adults with Down's syndrome (mean age: 31.511 (SD±13.233)) and 30 typically developing adults (mean age 36.448 (SD±14.098)). Independent t-test showed no statistically significant differences in age between the two participant groups (t=1.527; p=0.131). Similarly, there was no statistical difference in the gender distribution between groups (M-U: Z= -1.325; p=0.185). For instance, analysis of the gender distribution per group showed that ~57.7% of respondents with DS were female and 66.5% of respondents without DS were female.

The results of the different survey sections are presented in detail below:

1. The participants current eye care (i.e. last eye examination, use of glasses): The questions related to the frequency and type of eye examinations showed that in general most participants from both groups have attended an eye examination in the last 12 months (M-U: Z= -1.689; p=0.091), but that adults with DS tend to attend eye examinations more frequently than typically developing adults. For instance, a high percentage of participants in both groups reported having regular eye tests (Control group 63.33% and Group with DS 88.88%), but a higher percentage of participants with DS reported to attend more regular eye exams than the control group. This difference in eye examination frequency was statistically significant (M-U: Z= -2.465; p=0.015). In addition, a higher number of participants with DS attend hospital eye services appointments than typically developing adults (Control group: 3.33% and Group with DS: 31.1%). This difference was statistically significant (M-U: Z= -2.528; p=0.011).
2. The experiences of people with and without DS related to eye tests and receiving eye care: In general, most participants from both groups found booking an appointment an easy process and did not report any problems with doing so (M-U: Z= -1.490; p=0.136). Interestingly, when participants were asked about the duration of their most recent eye examination, while 40.7% of participants without DS who attend regular eye exams reported that their eye tests generally lasted less than 20 minutes, only 7.5% of participants with DS who attend regular eye exams reported this eye test length. Most participants with DS who attend regular eye examinations indicated that the length of their eye examination was between 20-40 minutes (participants without DS 40.7% and participants with DS 75%). This difference in eye examination duration was statistically significant (M-U: Z= -2.102; p=0.036). The following table presents this finding with more detail.

			Eye examination duration		
			Less than 20 min	20 to 40 minutes	More than 40 min
Group	Without DS	% within Group	40.7%	40.7%	18.5%
	With DS	% within Group	7.5%	75.0%	17.5%

Participants were asked about their ability to recall their experience during their last eye examination. Only those who confirmed to recall such experience were asked questions in relation to their last eye examination (88.9% of participants with DS and 96.4% of participants without DS; no significant differences $Z = -1.133$ $p = 0.257$). A number of these participants (63% of participants without DS and 70% of participants with DS) reported having been prescribed with spectacles in their last eye examination and no differences between groups in the prescription of spectacles was found (M-U: $Z = -0.517$; $p = 0.605$). From those participants who remember their last eye examination and where prescribed spectacles on their last eye exam, 52.9% of typically developing adults and 85.7% of participants with DS chose a new pair of spectacles after the eye test within the same practice. Those who chose spectacles on the same day and practice (from both groups), in general reported to be happy with their glasses on collection.

3. Eye care during the pandemic: In general, half of the participants from both groups stated that they waited longer to attend their regular eye examination during the COVID-19 pandemic (61.5% of participants without DS and 57.9% of DS; M-U: $Z = -0.597$; $p = 0.550$). In addition, a similar proportion of participants from both groups reported to have experienced an eye problem during the COVID-19 pandemic (27.6% of control participants and 33.33% of participants with DS; M-U: $Z = -0.564$; $p = 0.573$) and most of these participants were able to find help and support with this event at the time.).
4. Other health aspects: in the survey participants were also asked about their medical visits and their frequency. Unsurprisingly, more participants with DS reported attending a routine annual health check with their GP (73.3% of participants with DS vs 20% of participants without DS) and this difference between groups was statistically significant M-U: $Z = -2.965$; $p = 0.003$). In relation to these visits, the participant responses also indicated that while many participants with DS were recommended by their GP to have an eye examination, this was not the case for participants without DS. This finding was found to be statistically significant between groups (M-U: $Z = -2.012$; $p = 0.044$).

Main conclusions

1. Our study results suggest that most people with DS attend regular eye examinations and these are in general more frequent than in typically developing adults of similar age. In addition, more people with DS attend visits to the hospital eye services for their eye care than compared to typically developing adults of similar age.
2. The results of our survey do not show large differences in the experiences of eye care received between people with and without Down's syndrome. These findings support the view that eye care in the adult population with DS is similar to the eye care in adults without DS.
3. Similarly, eye care provision was similarly affected by the COVID-19 pandemic in people with and without DS.

References

SeeAbility (2016) "Delivering Equal Right to Sight" report available at <https://www.seeability.org/reports-research> [accessed 4th January 2021]

Wessex Voices (2020) "Improving Eye Care Across Wessex – Understanding the experiences of adults with learning difficulties and/or autism's access to sight tests and eye care" report available at <https://www.healthwatch.co.uk/reports-library/improving-eye-care-across-...> [accessed 4th January 2021]

Elam AR, Ehrlich JR, Lee P. Insights Into Eye Care Practice During COVID-19. *JAMA Ophthalmol.* 2020;138(9):988–989. doi:10.1001/jamaophthalmol.2020.3244