

Acceptability of telegenetics for families with genetic eye diseases

INTRODUCTION

Healthcare providers around the world have implemented remote routine consultations to minimise disruption during the COVID-19 pandemic. Virtual clinics are particularly suitable for patients with genetic eye diseases as they rely on detailed histories with genetic counselling.

AIMS

We present our model of setting up remote clinics for our ocular genetics service at Moorfields Eye Hospital NHS Foundation Trust (MEH) and assess the acceptability of virtual consultations and their preference of how this can be conducted to help plan our service.

METHODS

April-June 2019, the opinion of carers of children with inherited eye disorders attending the ocular genetics service at Moorfields Eye Hospital NHS Foundation Trust (MEH) were canvassed (figure 1.). Subsequently, between November 2020 and January 2021, sequential adult carers who had recently received a telephone consultation from the ocular genetics service were contacted and asked a short questionnaire about their experience.

Patient satisfaction with both genetic counselling and telemedicine was measured using two previously validated questionnaires: Clinical Genetics Satisfaction (CGS) and Telemedicine Satisfaction Questionnaire (TSQ) respectively.[1-3]

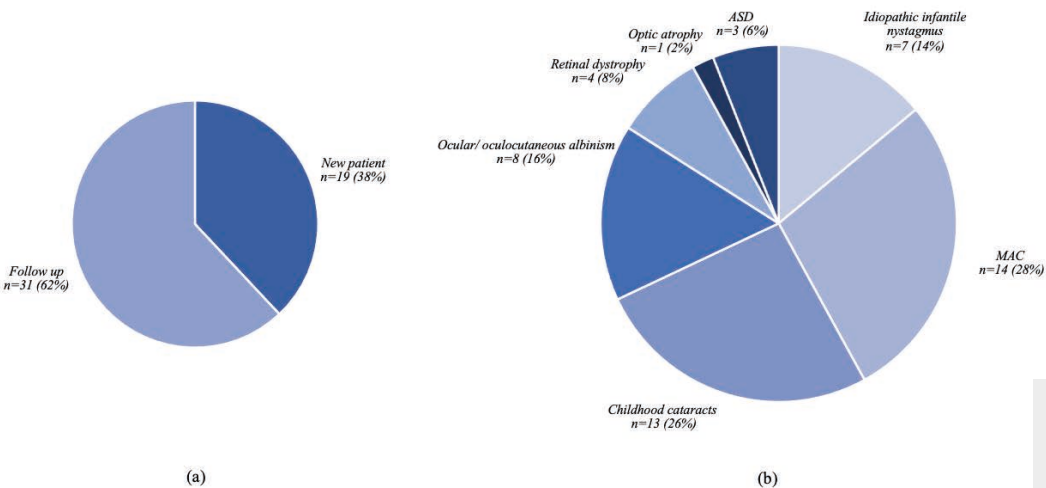


Figure 1. Proportion of patients attending new or follow up appointments and their ocular conditions. (a) Thirty one patients were attending follow up appointments. (b) Survey participants were carers of children with the following conditions

RESULTS

During the pre-pandemic canvassing, 65% of families (n=35/54) preferred to have investigations carried out locally rather than travel to MEH, with 64% opting for a virtual consultation to interpret the results. The most popular mode of remote contact was via telephone (14/31), with video call being least preferred (8/31).

Remote telephone consultations were implemented and 54 families who had received a telephone consultation mid-pandemic were contacted between November 2020-January 2021 to re-evaluate the acceptability of telegenetics using the CGS and TSQ. Overall, 50 carers participated (response rate 93%); 58% of participants found teleconsultations acceptable and 54% agreed they increased their access to care, but 67.5% preferred to be seen in person. Patient satisfaction was high with 90% strongly agreeing/agreeing they shared and received all necessary information.

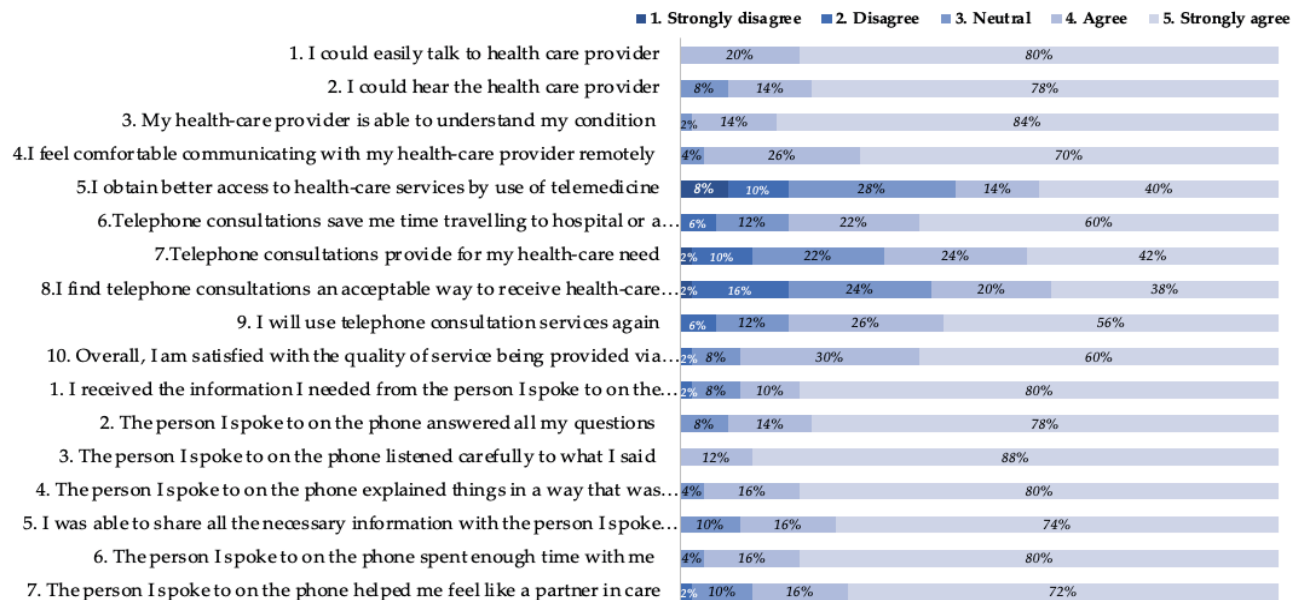


Figure 2. Participants were asked to rate their agreement to statements modified from the Clinical Genetics Satisfaction (CGS) indicator and Telemedicine Satisfaction Questionnaire (TSQ) on a Likert scale (1= strongly disagree, 2= disagree, 3= neutral, 4= agree, 5= strongly agree)

CONCLUSION

With the expansion of ocular genomic medicine and existing pressure on ophthalmology services combined with the current global pandemic means that now more than ever, alternative models of patient care need to be adopted. Measures to enable the continuation of routine and urgent health care delivery during and after the pandemic must be acceptable to patients. Genetic eye disease clinics are suitable for remote delivery and we have demonstrated that they are acceptable to families of children with inherited eye disorders.

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