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"A room full of strangers every day": The psychosocial impact of developmental prosopagnosia on children and their families

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ABSTRACT

Objective: Individuals with developmental prosopagnosia ('face blindness') have severe face recognition difficulties due to a failure to develop the necessary visual mechanisms for recognizing faces. These difficulties occur in the absence of brain damage and despite normal low-level vision and intellect. Adults with developmental prosopagnosia report serious personal and emotional consequences from their inability to recognize faces, but little is known about the psychosocial consequences in childhood. Given the importance of face recognition in daily life, and the potential for unique social consequences of impaired face recognition in childhood, we sought to evaluate the impact of developmental prosopagnosia on children and their families.
Methods: We conducted semi-structured interviews with 8 children with developmental prosopagnosia and their parents. A battery of face recognition tests was used to confirm the face recognition impairment reported by the parents of each child. We used thematic analysis to develop common themes among the psychosocial experiences of the children and their parents.
Results: Three themes were developed from the child reports: 1) awareness of their difficulties, 2) coping strategies, such as using non-facial cues to identify others, and 3) social implications, such as discomfort in, and avoidance of, social situations. These themes were paralleled by the parent reports and highlight the unique social and practical challenges associated with childhood developmental prosopagnosia.
Conclusion: Our findings indicate a need for increased awareness and treatment of developmental prosopagnosia to help these children manage their face recognition difficulties and to promote their social and emotional wellbeing.

Introduction

Faces are the most distinctive cue to a person's identity [1] and, arguably the most important visual stimulus in our lives [2]. Very early in life we use faces to recognize our caregivers and interact with them. In childhood, face recognition is important for making friends and developing social skills. As children mature, face recognition plays a role in finding partners, building careers, and maintaining social relationships. Thus, face recognition is important for both interpersonal development and status within the social world, beginning early in life and extending throughout adulthood.

The importance of face recognition is highlighted by cases of developmental prosopagnosia (DP), a neurodevelopmental disorder characterized by severe face recognition difficulties in the absence of deficits to low-level vision and intellect [3–5]. Although DP was once considered rare, recent reports suggest that it affects 2% of the population [6–8]. Despite this relatively high prevalence, only one study has directly examined the psychosocial consequences of DP in adults [9]. Participants reported feelings of embarrassment, guilt, and failure as a result of their face recognition difficulties. They indicated fear and avoidance of social situations, and, in extreme cases, chronic anxiety leading to long-term social isolation, limited employment opportunities, and loss of self-confidence. The authors likened the psychosocial consequences of DP to those resulting from other disorders like stuttering

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and dyslexia, that are commonly afforded special support and accommodations [9]. These findings led the authors to conclude that DP can have a lasting effect on formation and maintenance of social relationships.

Only one case study has examined the social consequences of DP in childhood [10]. 'Steve' (13-years-old) depended on non-facial visual cues such as clothing and hairstyle to identify others. Via semi-structured interview he reported specific concerns with academics, social interactions, and safety. The author concluded that, "children with prosopagnosia rarely have a wide circle of friends because friendships are difficult to develop and keep" (p.285) [10].

In the present study, we conducted semi-structured interviews with eight children and their parents. The goal was to use thematic analysis to extract themes that would provide insight in to the psychosocial consequences of impaired face recognition in a group of children with DP.

Method

Participants

Potential participants were selected from a group of children whose parents reported that their child experiences face recognition difficulties. Parents contacted us through our websites at Dartmouth College (www.faceblind.org) or the University of Minnesota (www.cehd.umn.edu/icd/research/yonaslab/). Children had to be English speaking, have no history of brain damage, have normal or corrected-to-normal vision, and have no diagnosis of Autism Spectrum Disorder (ASD) to be included in the study. In all, eight children (3 female; mean age: 9.25 years, range: 5–14 years) met the inclusion criteria and were classified as having DP (see diagnostic criteria below). There were no specific inclusion criteria for parents, who were included in the study if their children met the inclusion criteria.

Case descriptions of the eight children with DP are included in Supplementary Material 1. Information regarding participant identity has been removed, and pseudonyms are used throughout. This study was approved by the Behavioural Research Ethics Board at the University of British Columbia, the Institutional Review Board at the University of Minnesota, and the Committee for the Protection of Human Subjects at Dartmouth College. Informed consent was obtained for all participants and this study was carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki).

Procedure

Neuropsychological assessment

Children were assessed in their homes for general cognitive functioning (IQ, Wechsler Abbreviated Scale of Intelligence — II) [11], autistic tendencies (Autism-Spectrum Quotient — Adolescent Version [12], Children's Version [13]), face recognition deficits using the Cambridge Face Memory Test—Kids (CFMT-K) [14] and the Dartmouth Face Perception Test (DFPT), and for object memory using the Cambridge Bicycle Memory Test (CBMT). The CBMT is matched to the CFMT-K in format and difficulty. The CFMT-K is designed to test face memory and the DFPT is designed to test face perception. Our face recognition tests are described in further detail in Supplementary Material 2. Neuropsychological results for each child can be found in Table 1. For comparison, data from control participants are provided in Supplementary Material 3.

Diagnostic criteria

Very few good tests of face recognition exist for children [15]. Given this lack of precedence, we designed our own tasks of face memory and face perception, and established a relatively conservative approach to diagnosis of DP. We took two primary factors into account when classifying children as having DP: 1) anecdotes from parents provided evidence of face recognition difficulties in daily life (see Case Descriptions, Supplementary Material 1), and 2) DFPT scores were greater than 2 standard deviations (SD) below the control mean.

In adults, DP is typically diagnosed on the basis of face memory scores. Most of the children who met our diagnostic criteria also scored more than 2 SD below the control mean on the CFMT-K (see Table 1), however, the version used for younger children suffers from floor effects. Thus, even though the younger children (Chloe and Lorraine)

Table 1
Neuropsychological assessments. Pseudonyms, age, and gender are listed for each child. Measures include IQ (WASI-II = Wechsler Abbreviated Scale of Intelligence-II), Autism Quotient (AQ), face perception (Dartmouth Face Perception Test), face memory (Cambridge Face Memory Test—Kids), and object memory (Cambridge Bicycle Memory Test). IQ scores are indicated with percentile rank in parentheses. AQ scores are indicated with age-appropriate cut offs in parentheses. For DFPT, CFMT, and CBMT, scores that are >2SD below the control mean are indicated in with an * and in bold. Each child's scores were compared to scores from at least 12 children of the same age, except Chloe and Lorraine, whose scores were compared to scores from 7-year-olds, and Thomas, whose scores were compared to scores from 12-year-olds. Chloe was 5 years, 10 months, and 20 days at the time of testing. Her IQ test was scored using norms from 6-year-olds

Pseudonym	Chloe	Lorraine	Andrew	Harry	David	John	Rose	Thomas
Age/gender	5/F	6/F	8/M	9/M	10/M	10/M	12/F	14/M
Parent	Emma	Abigail	Julia	Jane	Sophie	Joanne	Jill	Lucy
IQ — WASI-II								
Performance IQ	120 (91st)	112 (79th)	122 (93rd)	102 (55th)	105 (63rd)	117 (87th)	86 (18th)	84 (14th)
Verbal IQ	138 (99th)	122 (93rd)	132 (98th)	134 (99th)	113 (81st)	120 (91st)	91 (27th)	122 (93rd)
Full scale IQ	133 (99th)	120 (91st)	131 (98th)	122 (93rd)	111 (77th)	122 (93rd)	87 (19th)	104 (61st)
Autism								
Autism quotient (cut off)+	57 (>76)	71 (>76)	49 (>76)	38 (>76)	16 (>30)	11 (>30)	26 (>30)	10 (>30)
Face processing								
Face memory (CFMT kids, chance = 33.3%)	37.5%	43.8%	**37.5%***	**52.0%***	**56.9%***	**34.7%***	**51.4%***	**38.9%***
z-Score	−1.16	−0.82	**−2.03***	**−2.35***	**−3.86***	**−6.94***	**−3.26***	**−4.71***
Face perception (DFPT, chance: 33.3%)	**35.0%***	**40.0%***	**40.0%***	**42.5%***	**65.0%***	**30.0%***	**47.5%***	**35.0%***
z-Score	**−3.66***	**−3.17***	**−2.21***	**−2.98***	**−2.57***	**−7.12***	**−6.63***	**−8.58***
Object processing								
Object memory (CBMT, chance = 33.3%)	77.1%	50.0%	79.2%	87.5%	68.1%	84.7%	72.2%	**48.6%**
z-Score	0.51	−1.22	−0.33	0.55	0.01	1.78	−0.39	**−3.10**
Interview duration								
Child	30 mins	41 mins	30 mins	20 mins	22 mins	18 mins	25 mins	17 mins
Parent	20 mins	30 mins	20 mins	30 mins	29 mins	25 mins	24 mins	68 mins