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Psychosocial consequences of developmental prosopagnosia: A problem of recognition

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Abstract

Objective: To provide the first systematic in-depth description of the consequences of developmental prosopagnosia (DP; 'face blindness') for psychosocial functioning and occupational disability, in order to determine what kind of professional intervention may be needed. **Methods:** Semi-structured telephone interviews were carried out with 25 people whose self-reports of face recognition problems were confirmed by impaired scores on the Cambridge Face Recognition Test. Thematic analysis was used to inductively identify and understand common psychosocial consequences of DP. **Results:** All participants described recurrent and sometimes traumatic social interaction difficulties caused by recognition problems, such as failing to recognize close friends, work colleagues, and family members. These problems often led to chronic anxiety about offending others and feelings of embarrassment, guilt, and failure. Most participants described some degree of fear and avoidance of social situations in which face recognition was important, including family and social gatherings, and meetings at work. Long-term consequences could include dependence on others, a restricted social circle, more limited employment opportunities, and loss of self-confidence. **Conclusion:** The potential for negative psychosocial consequences and occupational disability posed by DP is as great as that posed by conditions which are currently afforded professional recognition and support, such as stuttering and dyslexia. Wider recognition of the problems prosopagnosia can cause could reduce anxiety about social interaction difficulties by making it easier to explain and justify recognition problems to other people, including employers. Greater professional awareness could facilitate detection and referral of those requiring support with coping with social interactions.

Keywords: Developmental prosopagnosia; Qualitative research; Quality of life; Disability; Social phobia

Introduction

Developmental prosopagnosia (DP) is a condition defined by severe difficulty in recognising familiar faces [1,2]. Prosopagnosia was first studied as an acquired impairment arising as a consequence of brain injury, but it is now clear that severe face recognition problems can be present from childhood in the absence of any history of serious injury or disease. The reasons for failing to develop normal adult face recognition skills are not currently known, but appear to often include a genetic element [3,4]. DP may also result from prenatal or early minor brain damage, or inadequate visual input during key developmental periods (for example, due to severe myopia, or suppression of input from the left eye in amblyopia) [5].

It is now believed that the prevalence of DP may be as high as 2% of the general population [4]. However, the condition is seldom diagnosed since people with prosopagnosia can identify people in many situations by using general appearance and manner (including hair and clothes), semantic features (e.g., bushy eyebrows), voice, and contextual cues.

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Those with lifelong face recognition problems are often unaware that face recognition is typically effortless and reliable for others. Even if individuals notice their relative deficiency in face recognition, they are unlikely to suspect that this is due to a neurological problem, since there is little public awareness of DP.

The case histories and self-reports of some people with prosopagnosia (both developmental and acquired) suggest that it can have a severe impact on people's lives, resulting in avoidance of social interaction, problems with interpersonal relations, damage to career, and even depression [1,6–9]. Since DP interferes with social interaction it might predispose some people to develop social anxiety disorder, which is characterized by fear and avoidance of social situations which have the potential to cause embarrassment or humiliation [10,11]. It has even been suggested that DP could contribute to some cases of social developmental disorder [12,13].

There have been no previous systematic investigations into the experiences of people with DP, and so the purpose of this study was to provide the first in-depth description of the psychosocial consequences of DP. Our aim was to explore the ways in which DP might contribute to poor psychosocial functioning and occupational disability. This analysis would supply evidence relating to (a) whether there may be a need to provide support for people with DP, since no form of professional support is currently available; and (b) what specific psychosocial problems DP poses, and therefore what forms of support may be needed. We used qualitative methods to achieve our aims, since these are well suited to exploring new topics in an open manner, developing a rich, contextualized understanding of the topic and gaining insight into the diverse experiences of different individuals [14].

Method

Participants

Participants were recruited from a database associated with a website (http://www.faceblind.org) created by two of the authors (BD and KN). UK residents who had registered with the website and indicated their willingness to take part in future research (n=375) were invited by email to take part in a telephone interview.

To establish that these individuals had problems with face recognition, all potential participants were tested with a version of the Cambridge Face Memory Test (CFMT) [15]. This test is commonly used by many of the laboratories investigating prosopagnosia, because it has been shown to effectively discriminate between individuals with and without face memory deficits [15]. In the CFMT, subjects learn six faces at the start of the test and then must recognize those faces in novel views. There are a total of 72 items. Participants tested in the laboratory of BD (n=9) were tested with the original CFMT while participants tested remotely via the internet did the CFMT II. The two versions have identical designs, similar control means and distributions (CFMT=57.9, S.D.=7.9, n=50; CFMT II=58.8, S.D.=9.9, n=36), but involve different faces. Potential participants who scored 44 or below on the original CFMT were classified as prosopagnosic. In the original CFMT control group of 50 participants, only two scores were at or below this cut-off (one 44, one 43) [15].

Interviews were carried out with the first 25 individuals who met these criteria, from 106 who responded to the invitation. The scores of interviewees who had completed the original CFMT ranged from 23 to 44, with a mean of 39.0 (S.D.=9.9). The average for participants on the CFMT II was 36.5 (S.D.=6.3). These means are very similar to the mean of 37.0 (S.D.=6.1) for all DP scores on the original CFMT in published studies [3,7,16–19]. To ensure that participants with prosopagnosia acquired in adulthood were excluded, our first interview question was 'How did you come to realize you had prosopagnosia?'; none of the interviewees described adult onset (people who lose facial recognition abilities in adulthood are acutely aware of the loss) [9]. A few participants had other recognition problems (e.g., impaired recognition of objects, locations, emotions). Text from these participants was excluded wherever it was unclear whether difficulties they described were exclusively due to DP or could be related to other recognition problems; these instances were very few.

Qualitative researchers typically seek to develop an in-depth understanding of a person and their context that has theoretical relevance to understanding similar people and contexts [20]. For this purpose, it is considered good practice to carry out intensive analysis of data obtained from a relatively small sample that is nonetheless sufficiently diverse to provide insight into the views and experiences of a wide range of people and contexts [21]. Confirmation that the sample is adequate is provided when analysis of the data approaches 'saturation'; i.e., the inclusion of additional data does not produce significant new insights [22]. Our participants were 18 females and 7 males aged from 26 to 74 years (mean age 48 years, S.D. 14.8). All but four were educated to at least degree level; 20 were married, 4 cohabiting, and 5 single. Analysis of data from this sample did appear to approach saturation, providing some reassurance that the sample was sufficiently large and diverse to illustrate the range of psychosocial consequences typically encountered by people with DP.

Procedure

Ethical approval was obtained from the University of Southampton School of Psychology ethics committee. Data was collected by semi-structured telephone interviews lasting between 10 and 35 min (mean 17 min) carried out by the second and third authors. The interview schedule consisted of open-ended questions asking how the interviewee came to realize they had DP; how they felt about it;