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Doctors with dyslexia: a world of stigma, stonewalling and silence, still?

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Abstract

Introduction:

Dyslexia is a common learning difficulty, affecting 10% of the UK and worldwide populations. It is also becoming increasingly recognised within medical education.

There is little research into the experiences of doctors with dyslexia. This paper forms part five of a programme of research from the authors into the experiences of UK medical students and junior doctors with dyslexia.

Our research question is: “what are the lived experiences of medical students and junior doctors with dyslexia?”

Methods:

This is an Interpretive Phenomenological (qualitative) study. Dyslexic doctors were recruited from a single UK Foundation School. Participants were interviewed, in-depth, by telephone. Interviews were audio-recorded and transcribed verbatim. These underwent a thematic Template Analysis, which was verified in an iterative manner by both researchers.

Results:

Eight participants were interviewed. Core themes emerging for junior doctors' experiences were:

Their “disease”; perception from others; stonewalling; emotional responses; disclosure; influence on career pathway; and working life as the real word.

Conclusions:

Our results highlight a world of stigma, stonewalling, bullying and a reluctance to disclose. These results may suggest a need for education and public information about dyslexia, to begin to tackle this prejudice. Making adjustments to time in undergraduate exams may also not be enough. One of the most startling findings was the *fear* of being identified as “dyslexic”.

Keywords: Dyslexia, Interpretive Phenomenology, Specific Learning Difficulties, Junior Doctors, Lived Experiences

Introduction

Dyslexia is a common Specific Learning Difficulty, affecting 10% of the UK population (Siegel, 2006). It may be defined as a “learning difficulty that specifically impairs a person’s ability to read... Despite having normal intelligence” (National institute of neurological disorders and stroke, 2011). That said, the condition is an umbrella term, which may affect individuals in a variety of different ways (Shaw et al., 2016).

Dyslexia is not a new concern within the world of medical education. Three recent UK studies investigated the effects of providing “compensations” in exams (Ricketts et al., 2010, Gibson and Leinster, 2011, McKendree and Snowling, 2011). Two archaic US studies (a case study and a report of referrals for testing) provided richer data, but in a different time and place (Banks et al., 1995, Guyer, 1988). Research into the experiences of medical students and doctors with dyslexia has however been neglected until recently. There is a pressing need for it.

Newlands et al. (2015) used semi-structured interviews to explore the experiences of seven Foundation Year 1 (FY1) doctors with dyslexia (Newlands et al., 2015). They reported specific difficulties with: Communication; time management; disclosure; and anxiety.

It is our aim to give voice to the unspoken experiences of dyslexic doctors – aimed at FY1 and FY2 doctors. SS is dyslexic and his experiences provided additional insights within this study. This paper is part of an on-going programme of research. Here, we focus upon the themes relating to:

1. Working life as doctors; and
2. Experiences at medical school which influenced their working life.

It is our belief that this paper will be of interest and importance to medical professionals and students alike – providing insights into the struggles and strengths of dyslexic doctors. This not only sheds light on an untouched world within medicine, but can also raise awareness that dyslexic individuals can achieve great things in life and that they can become successful doctors.

Methods

We chose to adopt an Interpretive Phenomenological Approach for this study – to use SS’s insights to our advantage. His insider status enabled him to understand and empathise with our participants, whilst allowing our participants to tell their own stories. This approach aims to elicit people’s “lived experiences” – reporting these accurately and transparently. This methodology is recognised within “Qualitative Research in Healthcare” (Pope et al., 2006).

An invitation to participate was emailed to all doctors within a single UK Foundation School. Interested junior doctors were encouraged to contact us, via email. Participants had to meet the following criteria:

- Must have a diagnosis of dyslexia;
- Must be a qualified Medical Doctor;
- Must have qualified from a UK Medical School.

SS interviewed them, in-depth, over the telephone, about their experiences in medical school and in work. In order to avoid directing or pre-determining the shape of the interviews, these were unstructured. SS transcribed the audio-recordings verbatim, and a Template Analysis was adopted to generate themes. This analytic approach is well documented as a rigorous and appropriate analysis for this type of data (Pope et al., 2006).

Although we acknowledge SS as an insider, we made no attempt to predict or influence the results of this study. Each stage was closely scrutinised by both SS and JA to ensure the utmost scientific rigour. The analysis of transcripts and generation of our results were given extra attention from both researchers to prevent any introduction of “bias” – albeit the insider nature of interpretive phenomenological research may also be seen as a strength. This verification was performed both independently and together. The results are presented in the hope that “the participants speak for themselves” – we have quoted heavily from them to allow the reader to see and understand *their* issues.

Results

Seven FY1/FY2 doctors with dyslexia were recruited into this study. One additional doctor – a General Practice Speciality Trainee – contacted us asking to take part. We decided it was fair to include her. There is a preponderance of female to male participants – 7:1.

Their “disease”

Participants referred to their dyslexia as a disease. Several participants directly compared the condition to depression.

“I mean, I know it’s a disability, but I would consider it a disease anyway.” (P2)

“It’s a bit like depression” (P1)

“You wouldn’t say to a patient who’s got cancer ‘oh, no, you’ve not got cancer.’ You have to help them come to terms with it, and accept it.” (P1)

They believed that dyslexia was a common condition and that more education about it was needed within medicine.

“I think dyslexia is coming out a lot more... Just like depression is coming out a lot more... I think there needs to be a bit more education about it! Considering that 1 in 10 people have dyslexia.” (P1)

Others' Perceptions

Participants felt that the label of dyslexia still carries a great deal of stigma.

“... Dyslexia is actually quite a big thing. And there's obviously a lot of stigma behind it... Because it's so stigmatising... I think people will, erm, view me in a different light for it.” (P1)

Participants recalled numerous negative experiences relating to the way they were perceived at medical school by other medical students.

“Like, med students generally do act negatively when you tell them... I always felt like “oh, people think I'm stupid” at medical school... Like I remember someone saying to me ‘Oh you should just have cod liver oil tablets’... The thing is, they obviously didn't believe it's a real thing... It was really upsetting, honestly.” (P2)

“... Sometimes they (medical students) make you feel like you're a bit special. Or... They're like ‘you're [P3] the dyslexic.’” (P3)

“I have had people (medical students) say things like... ‘Who cares if you're dyslexic? You know, I don't think you should get special provisions.’” (P4)

Many participants recalled other medical students calling them “Fake Dyslexics”.

“They (medical students) called me a ‘fake dyslexic’, they were not accepting either... It's very dismissive. Which is not good!” (P1)

“I guess they (medical students) were like ‘oh, you know, you're doing medicine. Like, what you on about? You're like a ‘fake dyslexic’.’ And they're like ‘Oh. Can you fake your test?’” (P3)

Most attributed their negative experiences with other medical students to jealousy or a lack of knowledge.

*“I think dyslexia is very well **known**. But I think, sometimes people see it as an excuse.” (P4)*

*“Some people got **annoyed** that I got extra time. And some people got **annoyed** that I got a free computer, and a free printer...” (P2)*

Several participants also recalled negative experiences about the way they were viewed by doctors and other qualified healthcare professionals.

“Most people (doctors) don't see it as a real... They don't see it as a real disease. They just see it as made up.” (P2)

“I remember on firms and things... I was told “people aren’t dyslexic” or something like that. Some people would be like “oh, yeah, but is it a real thing?” (P2)

“I don’t think they kind of understand the psychological impact on people” (P1)

There was a strong feeling that participants had to prove or justify their condition to others – to fit the stereotype enough to be believed.

*“... No one **believed** me.” (P2)*

There was also strong belief that the people in general had warped or negative views of dyslexic people.

“I think it is seen as having a learning difficulty – i.e. being dumb.” (P1)

Stonewalling

There were multiple recollections of “stonewalling” from medical schools and postgraduate faculties. Some recalled negative responses from these professional bodies when requesting pen and paper in their undergraduate Observed Structured Clinical Examinations (OSCEs) or college membership exams – suggesting defensive or intransigent responses.

“When I wrote to them and complained about that particular scenario (in the OSCE), they basically said ‘Tough luck’.” (P4)

“And I challenged them for it (lack of paper in the OSCE)... They just said no. So I had to accept that... I thought that it was just stupid.” (P1)

“And they wrote back saying that... If I had asked for pen and paper beforehand, like before the session, I would have been allowed it. But in my defence... They hardly gave me any information...” (P2)

Some participants recalled a lack of support when it was asked for – resulting in cries for help. One participant was told that there was no support available for dyslexic doctors.

*“Because you feel as if you’re constantly trying to fight and say ‘will you **PLEASE** just offer be a bit of help? Or direct me?’... It really did surprise me when my tutor first told me (they didn’t know if any help was available). Then it shocked me with the programme director. And it really shocked me that I went as high as I could possibly go and **NOBODY** knew. You just think ‘how is this possible?’... Surely I’m not the first GP Trainee who’s ever asked for help.” (P8)*

It was strongly felt that this ignorance and lack of support would not be the case if someone with a physical condition were asking for support.

“Say for instance somebody was disabled in a wheelchair, I presume there’s pretty standard protocol for which help you would offer that person. It feels like it’s a bit hit and miss. So it’s like ‘Oh, we don’t really know what to do with you. Oh well! We won’t bother doing anything for you. It’s not important because it might only be a handful of people. And, actually, no one else has created a fuss, so we’re not gonna bother.’ That’s what it feels like.” (P8)

Geographical variations in support were also noted.

“So it really is the postcode lottery! That in some Deaneries an entire condition is denied, you know, in the South and accepted in the North.” (P8)

Emotional responses

Participants expressed a variety of emotions as a result of both their dyslexia and the way they were treated because of it. These were generally not positive feelings. Due to the workload and continual assessments, they felt isolated from their cohorts.

“I have felt as if I am the only person in the world with dyslexia trying to get through med school – and then trying to get through training, as well... You feel quite isolated. Isolated because... I was struggling. Isolated because I would have to spend so much longer, or I would appear to spend so much longer than anyone else.” (P8)

There was a sense of disappointment at cold and counter-productive responses they had received when asking for this help.

“The head of department’s response was a lot more cold and calculated... It wasn’t particularly nicely worded – it was a bit cut-throat really, I thought.” (P8)

“... This guy wasn’t very nice. And he accused me of lying (when claiming to need extra support)... And saying ‘should I even be a doctor’ because I am really unethical...” (P2)

Participants felt discounted – they were an annoyance because they had asked for help.

“... I find it a bit sad and disappointing that trainees with dyslexia are not offered any help and support...” (P8)

These negative experiences caused “Rubber-Banding” within the behaviour patterns and feelings of one participant – a phenomenon whereby an event in the present takes people right back to an earlier traumatic experience (Stewart and Joines, 1987). There was a clear pattern of stonewalling forcing her to repeatedly start her search for support anew. This caused her to become increasingly disheartened as time progressed.

“... It just made me feel as if I’m repeating history again... ‘Urgh, here we go again.’” (P8)

Participants recalled feelings of frustration at their own disabilities. These often related to being slower than other students and doctors.

“When you are a bit slower, obviously that’s... That’s very frustrating.” (P3)

The participants felt self-conscious about their dyslexia. It caused them to feel less intelligent, less worthy, than other doctors.

“Throughout my medical, kind of, career. I constantly... felt... self-conscious about it.” (P2)

“I felt like my BRAIN wasn’t as good as other people’s brains.” (P1)

Disclosure

Participants had a variety of feelings regarding disclosure in both medical school and in the workplace. Some felt that they were unlikely to disclose their dyslexia through fear of stigmatisation.

“I can’t turn around and say “I’m dyslexic, this is how I do it, just let me get on with it” because 1) that’s rude and 2) I don’t want to be telling everyone (on the wards) that I’m dyslexic.” (P1)

“ABSOLUTELY not at all! I just feel embarrassed. Embarrassed because I struggle... Medics are very highly competitive... So I think it’s probably NOT as supportive an environment as you would imagine it to be.” (P8)

There was a sense that medicine is a world in which disclosure is still dangerous if people wanted to both get into and succeed at medical school.

“... ‘Don’t say it at your interview’... ‘Don’t bring it up’... Or they won’t let you in. It (the application forms) said, you know, ‘No consideration will be taken so, you know, you will be expected to make sure that YOU’RE about to cope with the workload...’ It’s almost best not to write it, because they’ll end up quizzing you about it in your interview.” (P6)

Influence on career pathway

A strong theme emerging from the data was the influence dyslexia might have upon their career pathways and aspirations.

*“I think dyslexia is part of my personality, and it makes me who I am. And I think, you know, that who you **are** affects the kind of job you go into.” (P4)*

Several participants were considering pathways that they felt were less competitive and less likely to exacerbate their disability. Stressful working environments exacerbated their dyslexic difficulties.

*“When I’ve got time, when **I** see a patient by myself and I have the time to do so, my entries (in notes) are perfect... But when I’m on a busy ward round that’s running really quickly and I’m running around after a surgeon who’s seeing 6 patients at the same time, you can’t...” (P4)*

“... It makes me reluctant to apply for a competitive speciality.” (P5)

Membership of the Royal College of Physicians (MRCP) was specifically mentioned as being too difficult for participants, and the entrance exams potentially disadvantaging dyslexic candidates.

“No, I’m not doing MRCP... For MRCP you have to be super smart.” (P1)

*“I think it (MRCP part 1) was meant to be a 3 hour long exam. But obviously with the 25% extra, it was almost 4 hours... And then we had to do another paper. So that was basically 8 hours of... Kind of **INTENSE** mental working... I think that was too long... People accommodate by giving extra time, but they don’t necessarily see how it affects perhaps your performance. Because that is a long time to be working!” (P2)*

Several participants did, however, voice opinions against allowing dyslexia to influence their career pathway – one participant attributed this to pride.

*“And that might be, you know, a **silly** way of thinking about it. But I think that’s quite a **proud** way of thinking about it... It would upset me to think that I’d made a **change** because of that...” (P6)*

Participants' current career aspirations showed a tendency towards specialities which they perceived as having the heaviest reliance on communication skills – such as General Practice, Psychiatry and Elderly Care Medicine. Their current career aspirations are shown in Table 1.

ID Code	Current Career Pathway Aspiration(s)	Extra Comments
P1	1. General Practice	<i>"I just worry in general. I have done zero studying since my... Since being a doctor."</i>
P2	1. Gynaecology	<i>"In case I am so bad at the surgical side that I can kind of focus, as a consultant, more on medicine than on surgery." (Dyspraxia was seen as the main influence).</i>
P3	1. General practice	N/A
P4	1. Elderly Care Physician	<i>"Because I love working with people... I love seeing the whole picture. I would hate to be a pathologist – where I had to look at numbers all day or revise. Or, you know, write reports all the time."</i> <i>"I would much prefer to do- play to my strengths and do something that I enjoy and know that I would be good at. So I guess it has, kind of in a roundabout way, affected my career choice."</i>
P5	1. General Practice; 2. Public Health; or 3. Psychiatry	<i>"And I'll probably stick to a speciality which doesn't require... Which probably focuses more on sort of communication skills and like a patient centred approach."</i> <i>"... In somewhere like a GP surgery or in something like Public Health or psychiatry, erm... I feel comfortable in that setting... And (I can) make sure that I've not made mistakes."</i>
P6	1. Emergency Medicine; 2. Anaesthetics; or 3. Surgery	N/A
P7	1. General Practice.	N/A
P8	1. General practice; or 2. Staff grade doctor – if the exams continue to prove too challenging.	<i>"I even thought about getting out of GP training because of it... And do something like staff grade where I wouldn't have to sit exams."</i>

Table 1: Participant career pathway aspirations.

Working life – the real world

Participants stressed a view of working life as the "real world" – a jolt in transitioning from medical school – lacking continuity of both support and enjoyment.

*"I think, after medical school, the support is **GONE!** You are in the real world and people are less sympathetic. You won't get extra time examining patients... There is no sympathy or empathy and no understanding. And I feel very sorry for dyslexics who aren't as... who aren't as high functioning or don't have as good coping mechanisms as me." (P1)*

*“Because it’s associated with being a disability isn’t it. And no one wants to admit that they have a **fault**, or a... **Flaw**. You know. In real life.” (P4)*

This was associated with the belief that they were supposed to become ‘normal’ again once they were doctors.

*“But as a doctor you don’t get any (support) – you’re just expected to be kind of **normal** again, I suppose” (P2)*

Discussion

An interesting point arising from our interviews was the participants’ reasons for taking part in the study. They attributed doing so to two main reasons:

a. Some participants wanted to know how other dyslexic doctors felt – due to their own feelings of isolation on the matter.

“Just to find out... What other people, like, what their feelings and things are. And if anything can be done.” (P1)

b. Others wanted to raise awareness of and improve the current situation for future doctors and students – even if these improvements would not benefit themselves.

*“I **EVEN** said ‘even if you cannot help me in my training, I would really like to be able to help you develop something which could benefit future trainees.’” (P8)*

“I just thought, you know – fly the flag... Do something about it.” (P6)

We also note that, in the context of our results, the preponderance of female participants may highlight the fear of disclosure related to dyslexia – which may be felt particularly strongly from male doctors who need to cling to a strong, able image. Certainly many of our participants pleaded for more awareness of, and acceptance of dyslexia within the profession, and within medical training nationwide – including both the scientific aspects and the gravity of living with the condition. This emphasises the need to refute the excuse of “innocent ignorance” for gaps in support offered by postgraduate colleges and educational bodies.

Our data were rife with this pathologising mindset. Participants felt this way about themselves, and therefore believed that others must do to. It seemed to influence their self-worth and their relationships with others. The way in which they viewed dyslexia as a disease might have symbolised their subconscious desire to be absolved of fault – as if it were something caught, not a part of their natural biology. This could suggest a deep-seated level of denial about their condition.

Our study highlights issues that differ from Newlands et al. (2015). This may be due to differences in methods. They used semi-structured interviews (Newlands et al., 2015). The interview topic guide they used within their study might have also influenced their results by predetermining areas to be explored. Their results are therefore more targeted – albeit of high importance – than our, more exploratory, results.

Junior doctors with dyslexia felt they were able and that they should be accepted – but feared being regarded as inferior and possibly stigmatised. SS reported this in his autoethnographic account – knowing he was clever, but being frustrated at getting lower grades than medical students of similar intellect (Shaw et al., 2016).

There appeared to be an almost authoritarian view of dyslexia – “*should you even be a doctor?!*” – with an understandable fear of disclosure and associated inability to access support.

Our hope is not to dishearten those working within the medicine through shattering any disillusion. It is instead to highlight the need and the opportunity for change.

“It is harder to crack prejudice than an atom.” (Albert Einstein)

These experiences highlighted the need to standardise a minimum level of support for doctors with dyslexia across the UK. Within situations such as this, the Equality Act may have been compromised through this lack of provision. We need to put a stop to discrimination.

Study limitations

It is always a possibility that studies such as this might have an unrepresentative sample of their chosen population – we do not claim qualitative research of this nature to be generalizable. We hope we have shown something of the lived experiences of junior doctors with dyslexia, and are now working on a survey study to quantify these themes.

We acknowledge the potential for bias, which SS may have unknowingly introduced. We feel that, in both being aware of this possibility and by JA verifying the analysis and report, we have effectively minimised this risk.

Conclusions

There are still fantasies about, and stigmatisation of, dyslexia within the medical profession – suggesting that medicine may not yet be an equitable and supportive profession. Doctors with dyslexia are able practitioners who may have skills which arise from the ways they have to cope with dyslexia – which others do not possess. They are an asset to the profession, yet may feel they have to sideline their careers into “safer”, less competitive specialities. This study has revealed experiences of bullying, dismissive attitudes and stonewalling. The question is:

“How might we tackle these negative attitudes and behaviours to promote an inclusive culture within medicine?”

Our study has generated issues that we could not have foreseen when beginning this project. There is now a need to establish the generalizability of these experiences within UK doctors.

Take Home Messages

- There may be a stigmatisation of dyslexia within the medical profession.
- There may be a bullying problem (of dyslexic medical students) within medical schools.
- Professional Bodies may be overlooking the Equality Act (2010) and inadvertently stonewalling dyslexic doctors.
- Dyslexic doctors may not disclose as a result of these experiences and a fear of this stigmatisation.

Notes On Contributors

Sebastian Shaw is a final year medical student. He has an MSc in Medical Education, is a Member of the Academy of Medical Educators, and is an Associate Fellow of the Higher Education Academy. His main interests in education are dyslexia, social psychology and the student/trainee experience.

John Anderson is a medical sociologist. His career has mainly been in teaching and research in medical schools. He is a Senior Fellow of the Higher Education Academy and is currently a Principal Lecturer in Postgraduate Medicine, within the Division of Medical Education at Brighton & Sussex Medical School.

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Appendices

Declaration of Interest

The author has declared the conflicts of interest below.

The first author of this paper has dyslexia.