

**GPs' perceived self-efficacy in the recognition and management
of their autistic patients: An observational study**

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Abstract

Background: In the UK, the general practitioner (GP) plays a key role in the identification and management of autistic children, young people and adults. Yet there is a paucity of research on GPs' perceptions of working with their autistic patients.

Aim: To understand GPs' perceived self-efficacy in identifying and managing their patients on the autism spectrum and the factors that affect it.

Design and Setting: An online self-report survey was used.

Method: 304 UK GPs took part. The survey collected responses on: (1) participants' background, training and experience, both as a GP and with regard to autism; (2) a 22-item knowledge of autism questionnaire; (3) a 14-item self-efficacy scale targeting GPs' perceived confidence in identifying and managing their autistic patients; and (4) an open question eliciting participants' experiences on working with autism.

Results: 40% of participants reported never having received formal training about autism. Despite showing good knowledge of the key features of autism, participants reported limited confidence in their abilities to identify and manage autistic patients, with many citing a number of barriers that overwhelmingly focused on perceived failings of the current healthcare system.

Conclusion: There is an urgent need for improved local specialist service provision alongside clearer referral pathways for diagnosis to improve both GPs' confidence in caring for their autistic patients and the healthcare experiences of autistic people and their families. Local clinical commissioning groups (CCGs) are best served to assist GPs in ensuring that they can reliably detect the condition and make appropriate provisions for support.

Keywords: autism, general practice, mental health, diagnosis, identification, management

250 words

How this fits in

- There has never been greater interest in autism than there is at present and one central question concerns how and when autistic people are diagnosed and access services.
- GPs are crucial to that process but nothing is currently known about UK GPs' perceptions of working with their autistic patients.
- This study therefore examined GPs' perceived self-efficacy in identifying and managing their autistic patients and the factors that affect it.
- GPs reported remarkably limited confidence in working with their patients due in part to limited access to autism training and confusion around diagnostic and care pathways.

In the United Kingdom (UK), the general practitioner (GP) is often the first port of call for parents or individuals seeking assistance for a suspected diagnosis of autism spectrum disorder (hereafter, “autism”) (1). Responding to autism is a potentially challenging task for GPs. Changing definitions of autism (2), the substantial heterogeneity both between and within individuals (3), and the prevalence of co-occurring conditions in many autistic children and adults (4) all present serious difficulties to non-specialist clinicians.

The situation is further complicated by the fact that help is not necessarily sought for suspected autism per se. Parents often seek help for their child’s behavioural issues (1), while many adults’ initial concerns are about their mental health (e.g., anxiety, depression) (5). This latter issue is particularly critical given that autistic adults have been shown to suffer from premature mortality (6). **Beyond these autism-specific challenges, GPs are experiencing increased pressure in the wake of recent, radical changes to the primary healthcare system (7), including burgeoning caseloads and an increasingly important role for GPs in the commissioning of services.**

Parents of autistic children and autistic adults often report dissatisfaction with their healthcare experiences (1,5,8,9), especially regarding the diagnostic process. Particular frustration relates to the lengthy delays associated with the process (1,10). These delays can postpone access to services and limit confidence in their clinicians’ ability to help, during or after diagnosis (1,10,11,12). This, in turn, has led to calls for increased training on autism for GPs and other frontline professionals (13). The few existing studies – all conducted outside of the UK – have shown that GPs’ awareness of autism and appropriate referral and care pathways is variable (14-17). The only study to have investigated the perceived self-competence of primary care physicians in the United States found that this was predicted by the extent of their experience of autism and whether they had received previous autism training (18).

To understand these issues within a British context, we therefore conducted the first survey examining GPs' perceived self-efficacy in identifying and managing their autistic patients and the factors that affect it.

Method

Online survey

GPs were invited to take part in an online survey (powered by Survey Monkey), open between September and December 2015. Participants were recruited through convenience sampling methods, purposively targeting the membership of the UK's Royal College of General Practitioners as well as internet snowballing methods through social media.

The survey contained three sections and took approximately 10-15 minutes to complete. Part 1 comprised 19 items on the participants' background, including basic demographics (i.e., age, gender, ethnicity, location of and years in current practice and patient hours/week) and information regarding training and experience both as a GP and on autism.

Part 2 included a *Knowledge of Autism scale*, adapted from Stone (19) but modified to reflect **up-to-date scientific understanding of autism**. Twenty-two statements assessed participants' knowledge of early signs of autism, descriptive characteristics and co-occurring behaviours. Respondents rated these statements as 'true or false' (20). Scores on each item were summed to yield a total score. Higher scores reflect greater knowledge about autism. **Similar to previous knowledge-of-autism studies (14,20), the scale showed moderate internal consistency (Cronbach's alpha = .54). This is possibly due to the diverse nature of the items, which, despite focusing on autism, vary from socioemotional and cognitive characteristics to more descriptive (diagnosis, prognosis and intervention) features.**

Part 3 was a *Self-Efficacy Scale*. Perceived self-efficacy is a psychological construct concerned with people's beliefs in their capabilities to achieve a goal, which differs according to context and the behaviour of interest (21,22). The scale used in the present study was based on previous scales but was adapted to target specifically GPs' perceived confidence in their decision

making regarding working with their patients with (suspected) autism. Following Bandura's (21) procedure, we generated a 14-item scale, which respondents rated on a scale from 1 ('not at all confident') to 10 ('extremely confident'). Scores from each item were averaged to yield a mean self-efficacy score. Higher scores reflected greater self-efficacy. The scale showed excellent internal consistency (Cronbach's alpha = .95).

The survey ended with one final open question, eliciting participants' views and experiences on working with autistic people and their families.

All data were collected anonymously. All participants provided written informed consent. Ethical approval was granted by the Research Ethics Committee at UCL Institute of Education, University College London (REC 708).

Data analysis

Responses are presented descriptively, alongside correlational (to assess the relationships between knowledge of autism, perceived self-efficacy, training and other key variables) and regression (to examine potential predictors of GPs' perceived self-efficacy) analyses. Because of the relatively large number of comparisons, a p value of 0.01 was set. Participants' qualitative responses were analysed using thematic analysis (23). **We adopted an inductive approach, providing descriptive overviews of the key features of the semantic content of data within an essentialist framework. Two authors independently familiarised themselves with the qualitative survey responses, and met to discuss preliminary themes and make a list of provisional codes. These codes were then independently applied to each qualitative response. The authors reviewed the results on several occasions, resolved discrepancies and decided on the final themes and subthemes.**

Results

462 people responded to the survey. Responses were not considered for participants who (a) did not consent to participate (n=4) or (b) were not UK residents (n=31). Further, participants who did not progress past Part 1 (n=123) of the survey were excluded from the dataset. Table 1

shows background information on the final 304 participants. Most respondents were female (n=220; 72%), of White ethnic background (n=242; 80%) and had obtained their primary qualification in the UK (n=277; 91%). The majority of GP practices were broadly distributed across England, in which they had spent, on average, 10 years practising as a GP.

Quantitative analysis

Current practice, training and personal experience. Of the 304 GP respondents, 91% reported having at least one autistic patient currently in their care. Of these respondents, 48% had fewer than 10 autistic patients, 42% had between 11 and 30, and 10% had more than 30. In the past year, 91% had been approached by at least 1 patient about a suspected autism diagnosis, with the majority (n=237; 78%) being approached by up to 5 people. Most respondents felt that this number had increased since beginning their professional career (n=200; 66%). Few respondents (28%) reported referring to the diagnostic criteria for autism (1,24) and even fewer (19%) reported using any screening instruments, such as the M-CHAT (25), Social Communication Questionnaire (26) or Autism Quotient (27). GPs reported referring their patients with suspected autism to Child and Adolescent Mental Health Services (CAMHS; 62%), community paediatricians (59%), Community Learning Disability Teams (22%) and/or adult autism services (43%).

Almost two thirds (63%; n=193) of respondents reported not having received any training on autism during their **primary medical degree or specialist GP training**. Furthermore, almost two thirds of the sample (66%; n=200) reported not having received specific training (e.g., via Continuing Professional Development) on autism **since obtaining their qualifications**. Together, 40% (n=120) of participants reported never having received any training about autism (an additional 2% could not remember). Of those who had received training (n=178), **43% reported having received it during their primary medical degree or specialist GP qualification, 41% received specific training in the time since obtaining their primary qualification and 16% received training during both**. Encouragingly, those who completed their qualifications more

recently were more likely to have received training on autism during their degree, $r(297)=-.31$, $p<.001$. 63% felt that this training was ‘somewhat’ or ‘very’ useful.

Almost half of respondents (48%) reported having some personal experience of autism, either through being autistic themselves ($n=3$), or having an autistic child ($n=52$), other relative ($n=46$), or colleague/friend ($n=37$).

Knowledge of Autism scale. Respondents generally scored highly on the Knowledge of Autism scale ($M=88\%$ correct; $SD=9$; range=36–100%) (see Table 2). We calculated a *knowledge score*, adjusting for chance responding using the following equation (28):

$$R - [W/(n-1)]$$

Where R =number of right responses, W =number of wrong responses, n =number of items

Respondents’ scaled knowledge scores were expressed as a percentage of the total number of questions asked ($M=89\%$; $SD=16$; range=0–100%). Although GP respondents’ scores approached ceiling, it is noteworthy that the scale was sufficiently sensitive to detect differences between this sample of GPs and a sample of trainee teachers ($n=121$), who scored significantly lower ($M=78\%$; $SD=21$) than our GP respondents, $t(423)=5.95$, $p<.001$, $d=.60$ (29).

GPs’ scaled knowledge scores were not significantly associated with their age, $r(303)=.09$, $p=.14$, time in practice as a GP, $r(303)=.11$, $p=.06$, the number of autistic patients currently under their care, $r(303)=.09$, $p=.11$, or training on autism, $r(303)=-.01$, $p=.88$. Higher knowledge scores, however, were significantly correlated with greater personal connection to autism, $r(303)=.19$, $p=.001$.

Self-Efficacy Scale. Despite their impressive knowledge, overall, participants were only *somewhat* confident about their ability to make clinical decisions about the identification and management of their autistic patients ($M=4.78$, $SD=1.54$, range=1.50–9.07). The statements were given mode scores of between two and five, suggesting low-to-moderate perceived self-efficacy (see Table 3). GPs were least confident in deciding which medications to prescribe for autistic patients (arguably because there are few tried-and-tested pharmacological ‘treatments’ for

autism) and most confident about identifying stress in the parents/carers of their autistic patients.

Higher self-efficacy scores were significantly related to more training on autism, $r(297)=.18, p=.002$, and greater personal experience of autism, $r(303)=.31, p<.001$. Years spent practising as a GP, $r(303)=.12, p=.04$, number of autistic individuals under their care, $r(303)=.13, p=.03$ and knowledge of autism, $r(303)=.13, p=.02$, were also correlated with GPs' self-efficacy scores, although these correlations did not reach significance at the $p=.01$ level.

Predicting GPs' self-efficacy. We performed a multiple regression analysis on GPs' perceived self-efficacy with years spent practising as a GP, the number of autistic patients currently under their care, training on autism, and personal experience of autism entered stepwise into the model, together with knowledge scores. Respondents' personal connections to autism made a significant contribution, $F(1, 296)=31.76, p<.001, R^2=.10$. Autism training also explained unique variance, $R^2\text{change}=.03, F(1, 295)=11.46, p<.001$. There were no other significant predictors (all $ps>.09$), final model: $F(2, 295)=22.17, p<.001, R^2=.13$ (see Table 4).

Qualitative analysis

186 GPs responded to the open question. We identified two main themes (see Figure 1).

System-level factors. Participants reported frustration over *long delays between referral and diagnosis*, largely attributed to a lack of clear referral pathways, long waiting lists and limited resources. For one respondent, these delays were “completely unacceptable, particularly for adults”. Others noted the lack of joined-up services, leading to “a lot of passing from pillar to post of patients and their families”, with many left unsupported, “adding significantly to their distress”.

Respondents also reported *limited support from local services* post diagnosis. Once diagnosed, GPs felt a “sense of hopelessness about lack of appropriate help”, with “no offer of support, therapy or follow up”. Several commented on the pervasiveness of autism; “a life-long problem

that requires life-long support, which is rarely available”. Respondents stressed that *support for autistic adults was virtually non-existent*. They highlighted several challenges, including the complexity of diagnosing adults relative to children (particularly in light of co-occurring mental-health conditions), and difficulties “finding a place for them to be diagnosed” with some reporting “no specific local service for diagnosis and management for adults with suspected autism” who are “often left to fend for themselves”. They also underscored problems with patients transitioning from child to adult support services.

GPs highlighted the *lack of support for families*. They recognized the often-profound impact on families, including parents and siblings, emphasising that the strains on families “can be much greater than anticipated or readily recognised”. Many respondents felt the *need for clarity regarding referral pathways and resources* as these were “confusing” and “not at all clear”, leading to a lack of confidence “as to what is out there and who/where to refer”. Overall, respondents felt that “resources for supporting GPs are poor”. One GP remarked on how “the relatively few services for autistic children and adults are in a constant state of flux and impossible to keep up with”. Organisations working in silos was cited as a key problem. One respondent summed up the situation:

“Diagnostic pathways for children are complex locally with the hospital paediatricians now rejecting referrals completely. The community paediatricians will not see someone for assessment if they are under CAMHS and vice versa; the community paediatricians will also reject referrals which are not sent with a multidisciplinary referral form which requests information which we do not have access to (e.g., school, nursery information). Support for families going through this process is lacking, with delays, buck passing and frustration all round”.

Role of the GP in identifying/managing autism. Respondents described how *consultations are too short for such a complex condition*. Assessing and managing autism “takes more

than a 10-minute consultation” and “even with appropriate training, GPs do not have the resources properly to diagnose or look after patients/carers with autism”. Respondents were divided about the *remit of the GP*. Some felt that doing assessments and managing care is “well beyond the scope of what a GP can provide in the face of the deepening work load crisis and falling number of GPs” and that they should not “be taking the role of the specialist”. Others felt “that our role as GPs is to be aware of local services so that parents/carers/those with autism know where to turn for support”. However, many also noted that “it is very difficult to access resources” for their autistic patients, especially for “signposting to community resources” and that it would be “helpful to have more information to assist patients and their families”.

Regardless of these disagreements, respondents identified *the need for specific training on autism* including “in child development and communicating with patients” because GPs are often “the first port of call for these patients”. Some respondents were aware of the special considerations required when engaging with autistic patients around sensory sensitivity and coexisting anxiety.

Discussion

Summary

Despite showing robust knowledge about autism, GPs reported modest confidence in identifying and managing individuals with a (suspected) diagnosis. This confidence was related to greater autism experience, including personal connections and, to a lesser extent, prior training on autism. Qualitative analysis identified additional factors at the systemic level, which may have affected GPs’ confidence in working with their autistic patients, including lack of services, lengthy delays between referral and diagnosis, and, especially, a lack of clarity surrounding referral and care pathways. These largely-negative views are in spite of recent public policy (30,31) and service development initiatives (32,33,34) designed to improve service provision for autistic people and families. In light of existing disparities in the implementation of the

Department of Health's Autism Strategy (30,34), our results suggest an urgent need for improved local specialist service provision alongside clearer referral pathways for diagnosis.

Strengths and limitations

This is the first study to examine UK GPs' perspectives on working with their autistic patients in a reasonably large sample. *Although the sample size exceeded that of other, similar studies from outside of the UK (14-17), the response rate was low. Survey responses from general physicians are typically low (36) and could be enhanced in future with surveys mailed to postal and email addresses and including monetary incentives.* Almost half of respondents reported having some personal connection with autism. This number is not surprising given current prevalence estimates of autism (1% of the population) (37,38), but may also reflect a response bias, with those with a keen interest in autism more likely to respond. If true, then we may well be *underestimating* the issues at hand. *In this sample, personal connection to autism was significantly related to participants' knowledge of autism. It is therefore possible that non-responding GPs, who may have more limited personal connections to autism, also have less understanding of the condition, including ways to identify and manage it.*

Comparison with previous literature

Encouragingly, and in contrast to previous studies conducted outside of the UK (14-17,20), GPs' basic knowledge of the key autism characteristics was high in our sample. This should be somewhat reassuring to patients, who repeatedly attribute limited understanding of autism to their negative experiences of the primary care system (1,5,8).

Continual training on autism is still needed, however, especially given the heterogeneity of presentation and high rates of co-occurring conditions. Strikingly, more than one third (40%) of GPs reported never having received training on autism – during their degree or following their qualification. Given the significant challenges these respondents' reported, it is unsurprising that they expressed a desire for more autism training. Currently, GPs appear to rely on their personal connections of autism (through family members, friends, colleagues) as a source of tacit

knowledge – which may provide a more visceral and more nuanced appreciation of the realities of autism (14,18). An overreliance on subjective, personal knowledge could, however, afford a narrow, idiosyncratic view of what autism is, potentially causing clinicians to miss the signs in some individuals, potentially leading to disparities in healthcare provision (39). Improvements in disseminating objective knowledge through increased training opportunities, especially focused on underserved populations (e.g., autistic girls/women) should help to mitigate these concerns.

Implications for Research and/or Practice

GPs' confidence may well play a role in their decisions to refer – or not to refer – children or adults for further diagnostic assessment for autism (40). Efforts to enhance perceived self-efficacy are therefore much needed. Our findings suggest that initiatives targeted towards training on autism and greater clarity around referral pathways for autism should go some way to improve GPs' confidence in working with their autistic patients. Encouragingly, better understanding of autism amongst healthcare professionals is a key priority for the UK Government (13,30). And the Royal College of General Practitioners has produced educational resources designed to improve awareness of autism among GPs (32). Furthermore, we recommend that local clinical commissioning groups (CCGs) also play a role enabling GPs effectively both to share best practice and establish robust pathways to care. CCGs and GPs must work together with autistic people and families to ensure that they commission person-centred care that is respectful, accessible and attentive to the individual needs of those they support (8).

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Footnotes

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Competing interests All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work or activities of this type.

Ethical approval Research ethical approval was granted by the Research Ethics Committee at UCL Institute of Education, University College London (REC 708). All participants gave written informed consent.

Data sharing Participants did not give informed consent for data sharing, but the data are anonymised and the risk of identification is low. Data may be available from the corresponding author on request.

Figure caption

Figure 1. GPs' views and experiences on working with their autistic patients: themes and subthemes.