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Barriers to help-seeking for mental health among autistic young adults: a qualitative study

Abstract

Background: Autistic people are at increased risk of developing mental health problems. To reduce the negative impact of living with autism in a non-autistic world, efforts to improve take-up and access to care and support in early years – which will typically start with a GP appointment – must be grounded in the accounts of autistic young adults.

Aim: To explore how autistic young adults understand and manage mental health problems; to consider help-seeking as a focus.

Design and Setting: A cross-sectional, qualitative study. Participants from an existing cohort were purposively selected to represent a range of mental health conditions in this group, including anxiety and depression.

Methods: Nineteen autistic young adults without learning disabilities (23-24 years) were recruited. In-depth, semi-structured interviews explored how they understood and managed mental health problems. Data were analysed thematically.

Results: Young adults preferred self-management strategies. Multiple factors contributed to a focus on self-management, including: beliefs about the aetiology of mental health difficulties within the context of diagnosis of autism, communication differences, and a view that formal support was not available or not adequate. Families had limited awareness of professional support.

Conclusions: Young autistic adults without learning disabilities, and their families, may hold erroneous beliefs about autism and mental health. This may affect help-seeking and

contribute to an exacerbation of symptoms. GPs need to be alert that autistic young adults in their care may be experiencing mental health difficulties but may not recognise them as such.

Keywords

Autistic Disorder; Help-Seeking Behavior; Mental Health; Primary Health Care; Qualitative Research; Young Adult

How this fits in

The recently published NHS Long Term Plan identifies primary health care, including general practitioners as the first point of contact, as key to supporting improvements in mental health outcomes for autistic people. Despite evidence of the increased risk of mental health problems among autistic adults, particularly those without a learning disability, relatively little is known about how these are experienced and understood by autistic people, and the implications this may have in terms of the support GPs can provide. Based in the context of wider evidence that young people face barriers or are disinclined to seek help for mental health problems, this study explores autistic young adults' attitudes to managing and seeking help for mental health. It identifies a number of unique barriers to help-seeking for mental health difficulties experienced by this group which GPs need to be aware of, and identifies the need for GPs to feel confident raising mental health issues with autistic young adult patients.

Barriers to help-seeking for mental health among autistic young adults: a qualitative study

Introduction

Mental health is a key priority among the autistic community and clinicians (1, 2). A recent meta-analysis of research on the prevalence of co-occurring mental health conditions in autistic people found pooled prevalence estimates of twenty per cent for anxiety disorders and eleven per cent for depression in this population at any one time (3). These may result from challenges growing up in a non-autistic world. High rates of internalizing problems can stem from social isolation and bullying, and these can create a greater suicidality risk, especially in autistic people without a learning disability (4, 5). In the UK, the NHS Long Term Plan makes improving well-being for autistic people a priority for healthcare practitioners (6). However, there is no universal autism-specific mental health care pathway and access to autism-specialist mental health care is patchy (7). Recent research revealed that GPs may feel un-skilled to care for and support this population (8); this included concerns about differences in the presentation and communication of mental health problems.

This paper reports a study which explored how autistic young adults without learning disabilities manage their mental health. In order to identify and understand autism-specific issues, we situate it in the wider research on non-help-seeking for mental health difficulties among young people and young adults (9, 10). This literature points to multiple barriers to help-seeking, including difficulty communicating distress, self-reliance, negative views about support, and fear of stigma (11-16). Few studies report barriers to help-seeking in autistic young adults. Our study aims to provide evidence of these barriers.

Existing research suggests three inter-related issues may be relevant to understanding non-help-seeking and self-management in autistic young adults. First, young

people can be dissuaded from seeking help if they see distress as a 'normal' part of life (11). Autistic young people experience a different range of challenges in day-to-day life, and can have their own sense of what is 'normal' to them (17, 18). This may affect how mental health difficulties are perceived and managed. Second, autistic people frequently report negative experiences of primary care due to lack of expertise and healthcare systems not designed to meet their needs (19). Support which is seen as lacking or inadequate can leave autistic people reliant on themselves to manage symptoms and difficulties (20, 21). Third, communication differences between autistic and non-autistic people may be a further barrier to help-seeking (22). Drawing on findings from a qualitative study with autistic young adults, this paper adds to this evidence-base and considers implications for primary care.

Throughout we use *identity-first* language (e.g. 'autistic young people') rather than *person-first* language (e.g. 'people with autism') in view of autistic people's preferences (23). We maintain references to Asperger syndrome (AS) in respondents' quotes. While no longer recognised in terms of the American Psychiatric Association and DSM 5 (24), AS continues to be relevant as a label for those who received this diagnosis, as was the case for individuals recruited to this study. It is retained in the ICD-11 to refer to autism without a disorder of intellectual development, and with mild or no impairment in functional language (25).

Method

This article reports findings from a qualitative study of how autistic young adults without learning difficulties (IQ>70) interpret and manage their mental health difficulties. The study forms part of a programme of work on autism and mental health (*Removed for peer review*). It aimed to investigate how autistic young adults interpret and manage their mental health

difficulties. Two advisory panels, one comprised of autistic adults without LD, and including autistic young adults, and one for parents of autistic children, supported the study and the wider programme of work. For our study, this including identifying crucial topics to explore, and providing input and feedback on ways to facilitate interviews, data analysis, and dissemination. An NHS Research Ethics Committee (Ref: 14/EM/1282) approved the study.

Sampling and Recruitment

Recruitment was through an existing research cohort (n=171) of autistic young adults initially recruited as children (11-12 years) to an autism prevalence study and then retained as a longitudinal cohort (*Removed for peer review*). The cohort includes families who have consented to be contacted about other, related, research being carried out by the cohort study team or its collaborators. At the time of the study the cohort was aged 23 or 24 years and had recently taken part in a wave of data collection, including administration of mental health measures to the young adults and their parents. We aimed to recruit twenty autistic young adults without LD and, for a parallel study, their parents (reported elsewhere). Twenty was deemed sufficient for reaching data saturation while gathering 'rich' data (26).

A purposive sampling frame was used in order to recruit individuals without LD (defined by the cohort study as >IQ 70) who, at the point of interview, had experience of managing mental health problems that commonly affect this groups, principally anxiety and depression (see Table 1). Cohort Study Administrators provided the research team with an anonymised dataset for families who had agreed to contact regarding additional research. The dataset included scores on standardized mental health (self- and parent reported)

collected at 23 years. For ethical reasons, we did not approach young adults whose scores suggested they had recently experienced a period of severe mental ill health.

The Cohort Study Administrators approached families identified by the research team as potential study participants by telephone to introduce the study and seek consent to share their contact details with the research team. Families consenting to contact were mailed a letter of invitation and study information sheet. Also enclosed was a 'decline further contact' slip and reply paid envelope. Families not returning this slip were telephoned by a member of the research team a week after receipt of the postal invitation. During this call, the involvement of both the young adult and parent was discussed.

In total, 36 families were approached regarding taking part in the study. Six declined to take part, either at the initial contact by the Cohort Study Administrators or by returning the 'decline further contact' slip. Among the remaining thirty families, 19 young adults agreed to participate. Interviews were held within two weeks of the contact telephone call. Informed consent was secured at the time of the interview, before the interview commenced.

The Sample

The sample comprised seventeen young men and two young women aged 23 to 24 years. Most received an autism diagnosis before the age of eight. We sought to recruit positively for young women; however, they were under-represented in the cohort, reflecting a now recognised under-diagnosis of autism in girls in childhood (27). All but one described themselves as 'White British'. The sample, at the time of interview, had a range of experiences of anxiety and depression, see Table 1. Most attended mainstream school, and

several went into post-secondary education. Ten were in some paid employment, and nine were unemployed. Seventeen were living with their parents and two were in rented accommodation.

[Insert Table 1 here] (28-30)

Interview Procedure and Data Analysis

Study participants chose to be interviewed either at home or at facilities at a university campus they were familiar with visiting through their participation in cohort study.

Interviews lasted about one and a half hours and were supported using a semi-structured interview guide. To elicit rich data, the interviews started with a card sorting exercise which involved selecting phrases relating to autism (e.g. anxiety, communication problems, introverted, nervous exhaustion) and/or mental health (e.g. anxiety, depression, inability to cope, stress levels) that interviewees believed described their experiences, and then allocated to either autism or mental health. The cards were developed with the project's two advisory panels who guided the approach and provided words to include relating to autism and mental health. The selected cards were then used as prompts for the young adult to talk about their experiences and understandings of autism and mental health, and how they responded to, or managed, mental health issues. Following this, participants were asked to describe a time when they had experienced significant emotional distress or mental health difficulty. The interview then explored participants' perceptions and understandings of this experience, how they responded and what support they received at the time. The final section explored understandings and experiences of using mental health

services. Before formally closing the interview, participants were given time to reflect on what had been discussed. At the close of the interview, we shared written information about autism-specialist advice and support organisations including contact details.

All interviews were audio recorded and transcribed. An inductive approach to thematic analysis was used, which involved looking for patterns across the interviews and making generalisations in terms of themes (31, 32). This was started by one researcher reading the transcripts to identify themes. Themes were marked on the transcripts and used to develop a coding framework comprised of key themes and sub-themes (33, 34).

Discussions about the transcripts and themes within the research team helped refine the framework developed during this immersive process. To further validate the themes, we shared and sought feedback on the framework with the programme's two advisory panels. Once fully coded, data segments from each transcript were extracted into Word documents in the form of verbatim text and organized by theme. The lead researcher then led on a process of making detailed analytical notes that fed into the writing process through which data were further analysed (35). To ensure that the data had been fully analysed and comprehensively reported, the writings were continually refined over several redrafts. To refine the themes we present below, we developed our interpretations through a further reading of findings from other qualitative research on autism and how young adults understand and seek help for mental health (12, 13, 17, 20).

Results

The interviews elicited rich descriptions of 'anxiety-related' (e.g. feeling worried, fearful, or stressed) and 'mood-related' (e.g. low mood, low self-esteem, and feelings of a loss of

control) problems. In this paper we focus on data on how the young adults reported how they understood and managed such feelings and experiences. The following themes are presented: understandings of mental health and autism, beliefs about increased vulnerability, preferences for self-management, experiences of self-management, views and experiences of receiving support, and triggers for help-seeking. In the quotes below, personal details have been removed or changed to protect the respondents' anonymity.

Understandings of mental health and autism

Most interviewees discussed experiences related to their mental health which they believed were 'common' to, or shared with, other autistic young adults (36), but 'different' to what non-autistic young adults encounter (17, 18). Typically, the perceived difference was described in terms of frequency or duration, such as experiencing things more often or for a longer period, or intensity:

...it's normal to feel stressed... but I might feel stressed a little bit more. (YA06SF)

These experiences, mainly related to anxiety or low mood, could be brief or long-lasting. Participants typically identified specific triggering situations, such as social encounters or new environments, which reflected their understanding of autism-related difficulties. Frequency of experiences depended on how often triggers were encountered with impacts subsiding once a trigger had been removed or had become less threatening:

...when I started [college]... I was so nervous I couldn't speak clearly and I was shaking... it was a major change... I settled down after a few days... I got used to the routine. (DY02SM)

Some negative emotions were more intense than usually experienced (17, 18).

Often, these were linked to specific external events or set of circumstances, and within the context of a period of prolonged stress or difficulty, rather than solely attributed to autism:

...with my Asperger's and... a lot of my social problems... I don't feel like it's really easy for me to really confide in anybody. I think there [with support worker], I could finally find someone I could confide in, but... after things turned out the way they did [after the support worker left]... It just all fell apart, I just fell apart, me. (DY01SM)

There were consistent features in these more intense episodes. This included an indication that the experience was of a different severity and impact. The language used was more marked or graphic. Physical cues were typically an indication of their level of distress:

...it was quite severe... I could see myself dropping in weight. (DY07SM)

Beliefs regarding increased vulnerability

The majority of interviewees also voiced the view that autism made them more vulnerable to mental health difficulties compared to people who do not have autism. Specifically, they

believed autistic traits meant mental health symptoms were less likely to be contained and more likely to increase in intensity or adverse impact:

...the anxiety definitely is part of [autism]... I suppose everyone gets anxious... But most people are good at putting it to the back of their mind... I can't... I try to and then suddenly it just brings itself forward again. (YA01SF)

Thus study participants felt that, compared to non-autistic people, they needed to put more effort into managing their mental health. This was because they believed that they were not equipped with certain intrinsic abilities that they perceived non-autistic people as having.

...it's managed differently... regular people, for example, if they've got anger and frustration... they'll know what they need... there's that barrier there with people with Asperger; the anxiety and the... lack of confidence. (DY07SM)

The preference to self-manage

Many interviewees believed they had found ways to self-manage, or limit the impact of, experiences of emotional distress. In general, there was a preference to self-manage among those we interviewed, with few seeing asking for or accepting help as something they would do without hesitancy or difficulty:

...if people are trying to help... it probably would be for the best but... you're used to doing things your way and I guess you'd think someone's trying to interfere.

(YA08SM)

Within these accounts there appeared to be a lack of knowledge around what formal provision was available and how to access it.

Experiences of self-management

Interviewees described idiosyncratic, self-devised strategies they had developed. These ranged from those which managed the emotional distress being experienced to 'pre-emptive' strategies meant to reduce the likelihood of problems developing (20). Typical examples were pacing exposure to demanding situations, shifting attention from a trigger by withdrawing to a safe space or engaging in a distracting activity, and/or trying to cognize/rationalize (sometimes over a stretch of time) a negative experience until it became less distressing or less dominant in their thoughts.

...most I've ever tried to do is ignore it... keep my mind preoccupied on something else to try and get the anxious out, but that's quite difficult. (YA05SM)

...you just go into ... I call it my retreat. (YA08SM)

Self-management has been observed in young people generally. What appears to be different is the importance placed on informal sources of information or support (37). This may be due to difficulties communicating distress, differences in social networks, preferred coping strategies or, as we have already reported, how emotional difficulties are understood.

Negative views or past experience of help-seeking

Given the preference for self-management, we interrogated the data for evidence for attitudes to help-seeking. Few interviewees reported sustained help-seeking, beyond occasionally asking close friends or family, and there was little indication of meaningful engagement with statutory health care. This could be explained in several ways. First, some reported finding it hard to share their experiences with others. This could be linked to worries around how to communicate mental health problems (17), including being unsure about how to ask for help or not understanding how others would respond:

People did ask that; if you need help... you don't know if they mean it or not... I don't know how to communicate my problems and when people ask you think, in your mind, do they actually want to help. I don't know, you don't know how to communicate your problem to people, even to close friends of mine. (YA08SM)

Second, when asked directly about seeking professional help, interviewees expressed concerns or doubts about what could be provided. Some asked questions about whether formal provision would be preferable to self-devised strategies or, in a small

number of cases where that was considered to be an option, the more immediate informal support of friends and family:

I don't know if I'd ever be inclined to try and seek out a counsellor now... I'd rather just find out which of my friends are more open to the idea of me going to them if there's anything on my mind (YA10SM)

In other cases, participants expressed doubts about the extent to which any intervention could, or would, be beneficial. This included concerns that non-autism specialist professional support may be inappropriate and ineffective for them as autistic people:

...if you wanted to see like say a psychiatrist for anxiety and you've got Asperger's Syndrome, then ideally, you'd need to see somebody who specialises in that.
(YA11SM)

Third, for some, the reluctance to seek help was based on past experience. Several young adults described 'counselling' received in, or via, school during teenage years as unsatisfactory. Typically, this was attributed to that support being intermittent and/or not sustained:

... you make progress... but then that psychologist tries to leave, passes on everything to someone else and then it all gets lost and forgotten about. (DY01SM)

It appears that such experiences may also influence parents' views on seeking mental health support, with implications for successful signposting of support:

I asked mum and dad, I was saying "Oh do you think I need to see a psychiatrist?" and they said "No"... I've always assumed that I didn't then, but I've always thought that maybe if I did get a psychiatrist it would have helped. (YA05SM)

Although, as we reported earlier, some had recently sought help none were sufficiently down the path of receiving support to comment on its impacts and their experiences.

Situations triggering help-seeking from health care

Among those interviewed were a few who had experienced, for them, unusually intense (in terms of severity and duration) symptoms of emotional distress. Such experiences were regarded – either by the young adults or their parents – as being outside of the scope of self-management. There was evidence that when such situations were encountered, seeking support from external sources was, perhaps for the first time, considered.

I just wanted at least something to help me over, you know, just certain problems. I felt like, you know, I need someone to talk to about that. (DY01SM)

Parents had a considerable role to play in initiating this in several cases:

I: Was there a particular thought process around going to see the doctor?

A: Um .. mum, said I should really and I agreed with her. (DY04SM)

For the few where this had happened, this was the first time help had been sought from primary care. For some of these, it led to their GP referring them to adult mental health services, their first use of statutory health care (with respect to their mental health) beyond occasional interactions with school counsellors. As these experiences were relatively recent, it was not possible to explore perceived outcomes of using these services.

Discussion

Summary

Our findings contribute to a growing body of evidence on autistic young adults' experiences of mental health problems (17, 38), and expands research into barriers to help-seeking (9, 11, 13) by examining non-help-seeking in autistic young adults without learning difficulties.

Strengths and Limitations

As a qualitative study, and bearing in mind the population, recruitment was good – over half approached were interviewed. However, it may be that those not recruited had different experiences and understandings. Further limitations include the underrepresentation of

young women in the cohort from which the sample was recruited and the lack of diversity with regards to ethnic background. The study concerned autistic young adults without a learning disability and cannot, therefore, be taken to apply to autistic adults with learning disability. Furthermore, our participants were largely confident around participating in face-to-face interviews, and some had reasonably good outcomes (e.g. in terms of education and transitions into employment). We also note that our participants' experience of accessing and using services was limited, thus we were not able to explore service use and outcomes.

Comparison with Existing Literature

In our research, we identified three overarching factors which contribute to the decision to self-manage: 1) personal beliefs about mental health in autism, 2) a preference of self-reliance, and 3) views on support. These reflect themes in the literature on young people and help-seeking with respect to mental health problems, but from the perspective of autistic young adults.

First, research shows that how young people label mental or emotional distress (e.g. as 'normal' or severe) can promote an attitude of self-reliance (11, 12). Our findings suggest that for autistic young adults without LD, mental health difficulties can be perceived as 'different' in autism, and requiring different ways of managing (17, 18).

Second, similar to other research, we found a preference for self-devised strategies for difficulties autistic young adults were familiar with, which they may have found hard to communicate, and which they perceived as being not well understood by others (20). This is not problematic *per se*. However, knowing that self-management can become generalized for mental health difficulties of a range of severity (21), and given that more acute and/or

severe problems appeared to render usual self-management strategies ineffectual and/or unhelpful, it is possible that the young adults were not using the most adaptive strategies. For example, avoidance and withdrawal were both often cited as ways of managing emotional distress.

Third, and corroborating studies that identify a questioning of non-specialist services by autistic people (21, 39, 40), negative views about mainstream services, including primary care may also explain non-help-seeking (12). Negative past experiences of services can reduce help-seeking in young people (41); among our sample, none had any positive experiences. This may be due to systemic issues in health care for autistic people (19). Furthermore, we found that parents' observations of inadequate help in the past may also affect the way they guide or advise the young adult.

A disinclination to seek help for frequently experienced mental health problems meant that the young adults had only visited their GP when mental health difficulties had become acute. Typically, family members facilitated this in some way.

Implications for practice

The NHS (6) Long Term Plan sets out an aspiration to offer annual health checks to autistic people. Our findings lend support for the potential value of such checks. To address GPs concerns around lack of knowledge in this area, including mental health (8), these must be adequately resourced and come with appropriate training. This may be achievable; the Autism Core Capabilities Framework (42), to be published shortly, is likely to set out training requirements for those supporting annual health checks, and there is potential for that to focus on mental health. Other studies highlight (43) the need for GPs to have access to

autism-specialist services for advice and input and, where required, on which to refer.

However, regardless of whether annual health checks are rolled out, GPs will be the first port of call for any health concern given their position in primary care. Our findings provide important evidence for GPs on differences in the presentation and communication of mental health difficulties in autistic young adults without LD (and their families), and how those may relate to help-seeking behaviours and engagement with health care services.

They also point to the importance of GPs having a clear understanding of autism and mental health in the context of a diagnosis of autism.

More widely, we suggest these findings highlight the need for a preventive approach to reduce the risk of autistic young adults living with, over the long-term term, mental health problems which are amenable to intervention but, without appropriate care and support, may increase in severity and their impacts. Not unsurprisingly, this aligns with suggestions made elsewhere (10, 17). In addition, as well as making services accessible (18), our findings offer further understanding and appreciation of what autistic young people may need from those services. First, there is a need to address mental health literacy and communication among autistic young adults (and their family members) and, particularly, in the context of autism. This includes being able to identify mental health problems as things that can be resolved or, at least, eased, rather than as issues that are to be endured as an inevitable result of autism. It may be that some problems, which are related to growing up autistic in a non-autistic world, could be addressed with educational interventions (17). However we would suggest that GPs, for reasons explained above, have a role in providing care here and can facilitate support around understanding, communicating and managing mental health issues. The second is to ensure that through childhood, adolescence and young adulthood, in developmentally appropriate ways (and including via parents) autistic

individuals are supported to acquire adaptive strategies to manage their mental health, including when and where to seek help. This will require that GPs have access to clear guidance, and adequate specialist support, around differences in presentation and communication of mental health issues in this population, differences which we provide some information on in this article.

Finally, we note that similarities to non-autistic young adults (11, 13, 37) suggest that improving GP knowledge, understanding and communication around mental health in young adults generally would benefit a wider population, but with attention to differences in presentation and communication in autistic young adults.

Notes

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Ethical Approval

An NHS Research Ethics Committee (Ref: 14/EM/1282) provided ethical approval for the study.

Competing Interest

The authors have declared no competing interests.

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