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A Comparison of the Content and Nature of Worries of Young People with and without Autism Spectrum Disorder as they Transition out of School

And

Clinical Research Portfolio

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Chapter One: Systematic Review

The Employment Experiences of Adults with Autism Spectrum Disorder: A Meta-Synthesis of Qualitative Studies

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Abstract

Background: People with Autism Spectrum Disorders (ASD) struggle to obtain and maintain employment. Several proposed barriers include social and communication deficits, cognitive ability, mental health difficulties, and challenging working environments. Only a small number of studies exist which report people with ASD's own experiences of employment. To further understand this population's experiences of employment, a meta-synthesis of qualitative studies was carried out.

Method: Articles were searched for in six electronic databases, and reference lists of selected articles were hand-searched. Seven studies were identified and subject to quality assessment. A meta-ethnographic approach was used to synthesise the papers.

Results: Five third-order interpretations emerged: lacking social skills is a barrier to progress, feeling undervalued, misunderstandings and the need for clear communication, the desire for informed support and training, and sensory overstimulation increases work stress. These results suggested that employees with ASD could be successful in meaningful jobs under the right circumstances, but frequently there were barriers to success.

Conclusions: It would be enabling for employees with ASD if colleagues and employers had a better understanding of the condition, and if more job seeking and workplace support was made available. Further research should focus on developing employment interventions by seeking perspectives of employees with autism, and professionals working with them.

Introduction

Autism Spectrum Disorders (ASD) refer to a set of lifelong neurodevelopmental conditions, characterised by deficits in communication and social interaction, repetitive behaviours, and restricted interests (APA, 2013). Prevalence figures suggest the condition may be present in as many as 1 in 68 people (Centres for Disease Control and Prevention, 2012). Outcomes are generally poorer in those with autism compared to the general population. For instance, attendance in post-secondary education is lower (Newman et al., 2011) and isolation is common (Howlin et al., 2013). One particular challenge which individuals with ASD face is holding and gaining employment; with research indicating only 16% of adults with autism have full-time paid work (National Autistic Society, 2016). Employment rates for those with ASD are much lower compared to other disability groups (Roux et al., 2013). Furthermore, adults with high-functioning autism generally face underemployment (Autism Spectrum Australia, 2013), which is defined as working in a position whereby knowledge, ability, and experience are not fully utilized (Duffy, 2009).

Several barriers to successful employment have emerged. Research has shown that social difficulties can affect work performance (Sperry et al., 2005), and in some instances such challenges can lead to job termination (Bolman, 2008). Accounts from supervisors highlight that communication difficulties in employees with ASD can negatively influence job performance (Hagner & Cooney, 2005), and these difficulties can affect engagement in team projects (Richards, 2012). Interactions can be problematic prior to employment, with job interviews proving to be a significant obstacle (Strickland et al., 2013). Cognitive ability may play a role, as individuals with high-functioning autism can display difficulties in problem-solving and organisation, despite average or higher than average IQ (Barnhill, 2007). The environment may also contribute to job complications, as adjusting to workplace routines can be difficult (Keel et al., 1997), as well as habituating to workplace noise (Burt et al., 1991). Parents of individuals with high-functioning ASD cite anxiety as a barrier for post-secondary success (Camarena and Sarigiani, 2009), indicating that mental health could also be a significant component.

In general, unemployment and underemployment can detrimentally affect mental and physical wellbeing (Rosenthal et al., 2012). Employment has been found to improve quality of life in those with autism (Garcia-Villamisar, 2002), and enhance cognitive abilities (Garcia-Villamisar & Hughes, 2007). Employees with autism have been evaluated highly by their supervisors (Hagner & Cooney, 2005), and research indicates that companies appreciate their dependability and low absenteeism (Howlin et al., 1995). Furthermore, the reported lifetime cost of supporting someone with ASD without an intellectual disability in the UK is reported to be £0.92 million (Buescher et al., 2014), thus increased employment would be beneficial economically. Employment outcomes remain poor despite an increasing number of adults with ASD utilising support services (Burgess & Cimera, 2014), thus it is important to find out more about the needs of this population in an employment setting.

The majority of qualitative research regarding lived experiences in ASD investigates the views of significant others in the person with ASD's life, such as parents or carers. However, there is a sufficient but disparate range of studies exploring the employment views of people with autism. For instance, Muller et al., (2003) sought perspectives for improving job retention services by interviewing 18 adults with high-functioning ASD. Grounded theory analysis found barriers to employment success such as difficulties in completing job applications and acclimatising to new job routines, as well as facilitators including autism awareness training for employers (Muller et al., 2003). Another study by McKnight-Lizotte (2018) utilised general inductive analysis to explore the work-related communication experiences of 6 young adults with Asperger's Syndrome. Findings showed that anxiety and communication stressors were heightened during job interviews, and that communicating with colleagues and customers could be challenging (McKnight-Lizotte, 2018). To date, a qualitative systematic review exclusively examining the employment experiences of those with ASD has yet to be conducted, further warranting the need for a meta-synthesis in this area. Synthesising qualitative studies can increase understanding of a topic and provide new insight into participants' experiences (Ring et al., 2011). In the context of employment, synthesising viewpoints from those with ASD could help identify gaps in services or provide recommendations for professionals. This is especially important considering that many individuals with ASD are not receiving the vocational support services they require (Roux et al., 2015).

The current review aims to examine and understand the employment experiences of people with autism. Synthesising the findings of qualitative research in this area will help shed light on the variety of participants' experiences. Outcomes will also help uncover the job-related needs of those with ASD. This could potentially assist employers regarding how to best manage these needs and allow employees with ASD to be successful in the workplace.

Methods

Search Strategy

Six databases were searched, with advice sought from a university librarian. Through discussions with the librarian, the six databases were chosen due to their relevance to the topic areas of employment and autism, as well as on the basis of a social science focus. The databases MEDLINE and EMBASE were searched via OVID. CINAHL and PsycINFO were searched via EBSCO host. ASSIA was searched via ProQuest, and Web of Knowledge Core Collection was searched on its own platform.

Search Terms

Search terms were identified by the researcher following examination of previous relevant systematic reviews, as well as through consultations with an expert librarian and university supervisor. A broad and inclusive approach using free-text was employed. This has been recommended due to the challenges in detecting qualitative research electronically (Britten et al., 2002; Centre for Reviews and Dissemination, 2009). Terms were linked using Boolean operators “AND” and “OR”; and truncation was applied where appropriate. The following keyword terms were searched on the 20th of April 2019:

1) ASD OR ASC OR Autis* OR Asperger* OR Pervasive Developmental Disorder OR PDD

2) Employ* OR Work OR Occupat* OR Job OR Vocat* OR Placem*

3) Qualitative OR Grounded Theory OR Interpretative Phenomenological OR Narrative OR Thematic Analysis OR Social Constructionis* OR Experience* OR Content Analysis OR Grounded OR Interview* OR Ethnograph*

4) 1 AND 2 AND 3

Titles, abstracts and full-text articles obtained from the search results were reviewed against the inclusion and exclusion criteria. A flowchart of this process is outlined in Figure 1.1**.** Contents pages from the year 2000 of the journal *Autism* and the *Journal of Autism and Developmental Disorders* were hand-searched to locate potential studies not found electronically. Reference lists for identified papers were also hand-searched.

Inclusion Criteria

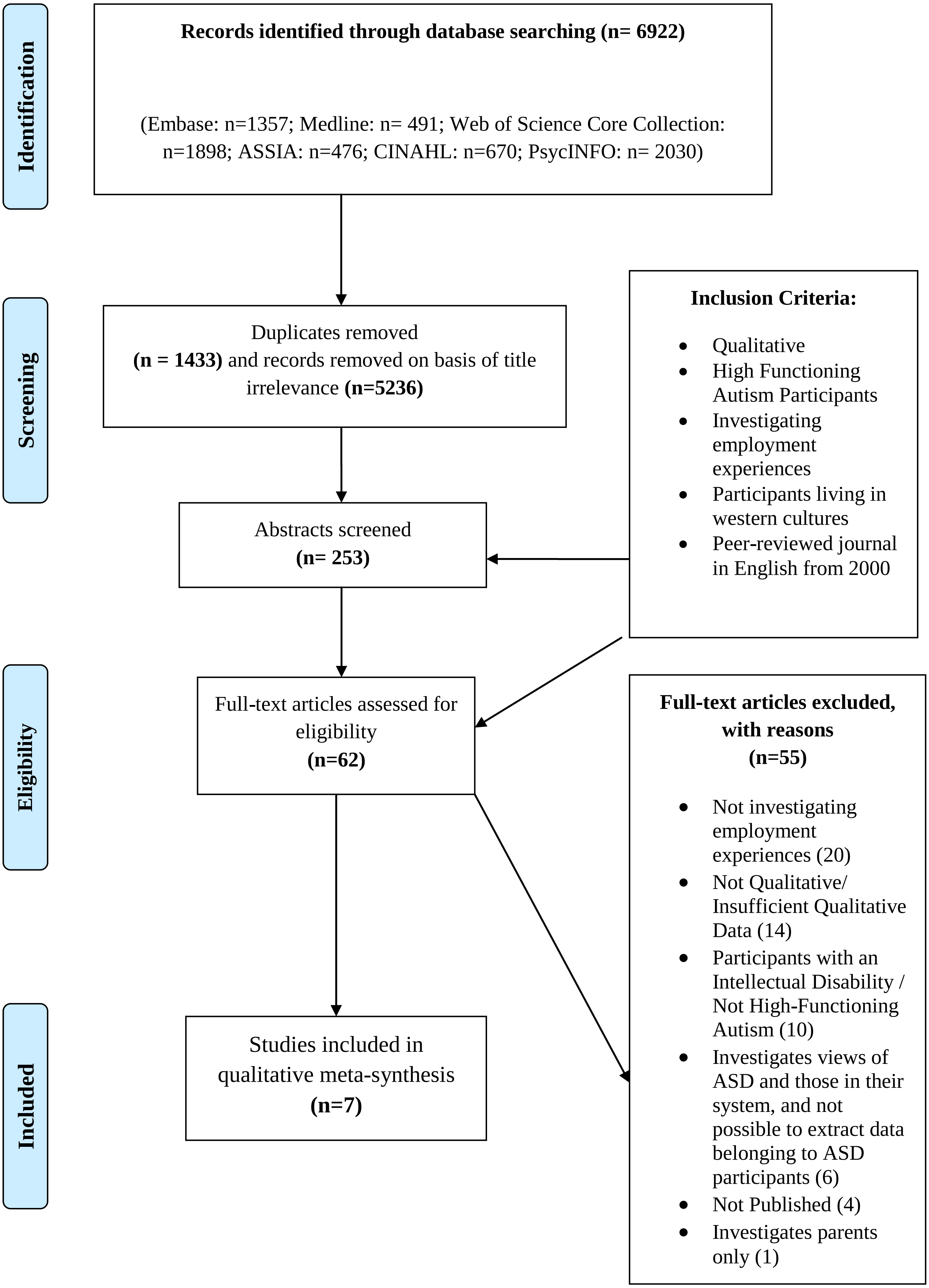
- Qualitative studies or studies with a qualitative component
- Studies including participants with High-Functioning Autism Spectrum Disorders;
- Studies investigating participants' experiences of employment (work experiences);
- Published from the year 2000 onwards;
- Published in a peer-reviewed journal in English;
- Includes participants living in western cultures. Western culture refers to the heritage of norms, values, customs and beliefs originating in and associated with Europe. It includes countries beyond Europe whose histories are connected to Europe by influence, such as countries in the Americas or Australasia.

Exclusion Criteria

- Studies investigating the views of others involved in the person with ASD's system (e.g. parents), where it is not possible to extract the data belonging to the participants with ASD
- Participants with an intellectual disability
- Unpublished, case studies, or book chapters.

Unpublished studies are absent of peer-review, therefore may lack the validation obtained from an official refereeing process. Consequently, unpublished literature was considered outside the scope of this review.

Figure 1.1: PRISMA Flow Diagram of the Screening Process and Study Selection



Quality Rating Method

Walsh and Downe (2006) developed a tool which has been widely used to appraise qualitative studies (Walsh & Downe, 2006). The authors assert that evaluating qualitative studies is vital for establishing credibility. In the current review, the appraisal tool was employed to assess the included studies, with an adapted scoring method (shown in Appendix 1.1). This tool incorporated 28 items relating to core aspects of qualitative research including: the scope and purpose of the research, design, sampling strategy, analysis and interpretation of the data, researcher reflexivity, ethical dimensions, and the relevance. If a criterion was met, it was marked as present, whilst if a criterion was not indicated, it was marked as absent. For reliability purposes, an independent reviewer (Clinical Psychologist) appraised the articles, and discrepancies in quality ratings were resolved through discussion.

It can be difficult to recognize methodological faults in qualitative research, because of the diverse theoretical underpinnings and study designs used (Dixon-Woods et al., 2004). Moreover, word limits may prohibit the reporting of methodological information. There is no established gold standard for rating qualitative research, and tool-based approaches have been found to be no more effective than unprompted judgement (Dixon-Woods et al., 2007). Therefore poor reporting or ratings may not necessarily equate to a poor quality study. Furthermore, certain synthesis approaches, including meta-ethnography, are less committed to the concept of quality appraisal, with this approach tending to be more inclusive than aggregative synthesis methods (Barnett-Page & Thomas, 2009). Studies rated as less well-conducted can still provide valuable new insights into a phenomenon (Atkins et al., 2008). As a result of the reasons outlined, the ratings in the present review were used to facilitate a discussion around strengths and weaknesses, as opposed to excluding papers not meeting a certain standard.

Method of Synthesis

Meta-ethnography was chosen to synthesise the findings; an approach developed by Noblit and Hare (1988). It involves induction and interpretation, and provides new insights into the topic being analysed. It is a widely-established technique (Atkins et al., 2008), and permits studies utilising various qualitative methods to be synthesised alongside one another (Campbell et al., 2003). There are various methods of synthesising qualitative literature (Barnett-Page & Thomas, 2009). Some synthesis approaches aim to describe or aggregate findings, whilst others aim to interpret findings to develop conceptual understanding or theory. The current review aimed to develop an understanding of the employment experiences of those with autism, as opposed to summarising findings, thus meta-ethnography was considered the most appropriate method for the review objective (Campbell et al., 2011). Integrative approaches, such as narrative synthesis, tend to extract and summarise data where the concepts are well-defined, for instance in studies reviewing barriers and facilitators of accessing interventions (Hill et al, 2013). In addition, thematic synthesis draws conclusions from recurring themes in the primary literature, an approach often used to answer questions about need, appropriateness and acceptability of interventions or policies (Ring et al, 2011). Given their scope, the latter approaches were not considered consistent with the aim of the current review.

Noblit and Hare describe seven steps to a meta-ethnography, illustrated in Table 1.1.

Table 1.1: Meta-ethnography Stages

Stage	**Description**
Getting started	Determine research question
Deciding what is relevant to the initial interest	Defining the focus of the synthesis; locating relevant studies; making decisions on inclusions; quality assessment
Reading the studies	Becoming familiar with the content and detail; begin to extract 'metaphors' or emerging themes
Determining how studies are related	Create a list themes of and metaphors; juxtaposition of above; determine how themes are related; reduce themes to relevant categories
Translating studies into one another	Arrange papers chronologically; compare paper 1 with 2, and the synthesis of these papers with paper 3 and so on
Synthesising translations	Transposing concepts and explanations from studies into encompassing third-order interpretations
Expressing the synthesis	Presentation of results; publication of findings

The process of meta-ethnography requires subsuming concepts and themes regarding a certain topic into “higher order constructs” (Noblit and Hare, 1988). As such, the researcher extracted quotations, themes, and author interpretations from each study. The idea of higher-order constructs has evolved since Noblit & Hare’s initial work (Atkins et al., 2008). First-order constructs have been defined as the participants’ understandings, from which second-order constructs are developed: the researchers’ interpretations of participants’ experiences. Second-order constructs can be interpreted further to develop third-order constructs: the meta-ethnographer’s interpretations of the researchers’ concepts. This leads to conceptual development beyond the level found in each individual study, allowing for novel understandings of participant experiences.

Translating studies into one another can involve three main methods: reciprocal translation, refutational translation, or line-of-argument synthesis. Reciprocal translation is used to synthesise concepts that are similar in meaning, refutational translation synthesises contradictory concepts, whilst line-of-argument synthesis occurs when the studies identify different aspects of the topic that can be drawn together in a new interpretation (France, Uny, et al., 2019). There were clear similarities in relationships between the studies in the current review, giving rise to reciprocal translation.

Results

Data Extraction

Table 1.2 displays the key features of the seven included papers. Country, study aims, data collection method, analysis method, relevant themes, and participant demographics with corresponding employment status were extracted. Although all studies investigated employment, some studies explored additional lived experiences (Griffith et al., 2011; Baldwin & Costley, 2016; Sosnowy et al., 2018), and only qualitative data relating to employment experiences were extracted. Likewise, Sosnowy et al. (2018) interviewed parents of young adults with ASD, but only data from individuals with ASD were included in the current review.

Table 1.2: Study Characteristics

Study Citation and Country	Aims	Data Collection Method	Analysis	Participants	Themes Relevant to the Review
Muller et al. (2003) **USA**	Seek perspectives on strategies for improving job retention services for those with ASD	Individual semi-structured interviews	Grounded Theory	18 people with a formal or informal diagnosis of Asperger Syndrome or other ASDs Age Range: 18-62 Gender Split: 13 M / 5 F Employment Information: 6 full-time, 5 part-time, and 2 student/volunteer currently. 5 currently unemployed	i) Diverse Vocational Interests ii) Unemployment iii) Underemployment iv) Negative work experiences v) Positive work experiences
Hurlbutt & Chalmers (2004) **USA**	Provide information about issues regarding employment of adults with high-functioning ASD, and recommendations for preparing individuals with ASD for successful job experiences	Individual interviews	Qualitative - Unknown	6 participants with self-disclosed high-functioning ASD or Asperger Syndrome Age Range: 25-65 Gender Split: 3M / 3F Employment Information: 4 currently in work (hours unknown), 1 volunteer, 1 unemployed	i) Unemployment and Underemployment ii) Social Skills, Communication and Sensory Issues iii) Recommendations for Aiding Workplace Success
Griffith et al. (2011) **Wales, U.K.**	To explore how individuals in middle adulthood with high-functioning ASD perceive its effects on their lives, their previous experiences of support, and current support needs.	Individual semi-structured interviews	Interpretive Phenomenological Analysis	11 adults with a formal diagnosis of Asperger Syndrome or actively in the process of obtaining a formal diagnosis. Age Range: 37-57 Gender Split: 7 M / 4 F Employment Information: 4 full-time and 1 part-time currently. 1 full-time education, 2 volunteer and 3 unemployed currently.	i) Employment Issues

Krieger et al. (2012) **Switzerland**	Gain knowledge about contextual factors which contribute to successful labour market participation in adults with high-functioning ASD	Two individual semi-structured interviews within a 4-week period	Hermeneutic and Narrative Approach	6 Adults identifying with Asperger Syndrome Age Range: 30-45 Gender Split: 4M / 2F Employment Information: 3 full-time and 3 part-time	i) Social Context: To feel socially secure and be familiar with social environments ii) Cultural Context: To achieve cultural competence iii) Physical Context: To be protected or offended
Baldwin & Costley (2016) **Australia**	To provide an overview of the health, education, work, social, and community activities of adult females with high-functioning autism	Questionnaire with open-ended questions	Thematic Analysis	82 Female Adults who reported to have high-functioning autism Age Range: 18-64 Gender Split: All Females Employment Information: Of those not in education, 62% had a paid job currently. Within this group, 60% were full-time and 40% part-time.	i) Being pinned back from fulfilling job and career potential ii) Social challenges in work iii) Bullying and overt mistreatment iv) Executive function deficits as a challenge in work v) Difficulties in securing part-time work vi) Aspirations for further study and new careers
McKnight-Lizotte (2018) **USA**	To explore the work-related communication experiences of individuals with ASD and post-secondary education	Individual semi-structured interviews	General Inductive Analysis	6 adults with a self-reported diagnosis of AS Asperger Syndrome Age Range: 26-37 Gender Split: 4M / 2F Employment Information: 3 full-time and 3 part-time currently	i) Job Interviewing for Success ii) Negotiating co-worker interactions iii) Supervisory interaction, instruction, and feedback iv) Handling customer intercommunication v) Communication-oriented coping strategies
Sosnowy et al. (2018) **USA**	To seek perspectives of parents and young adults with ASD to understand how they view desired outcomes, barriers, facilitators, and identify strategies, services, and supports	Individual semi-structured interviews	Grounded Theory	21 Parents of adults with ASD, and 20 adults with a self-reported diagnosis of ASD. Age Range of adults with ASD: 18-29 Gender Split of adults with ASD: 11M/6F/1 non-conforming/2 unknown Employment Information: 6 in full-time job currently	i) Numerous barriers and few facilitators in finding and keeping employment ii) Workplace accommodations seen as primary facilitators to success, but not always available

Quality Review Results

Table 1.3 shows the quality ratings for each paper. Each paper described the scope and purpose of their research. Likewise, each paper outlined a clear rationale for their study, and thoroughly contextualised their research within the existing literature. The one exception was the paper by Hurlbutt and Chalmers (2004). They did not provide a thorough background for their study and their rationale was vague.

Study design and appropriate justification for the choice of qualitative methods were included in most studies reviewed, and appropriate epistemological underpinnings outlined. Once again, the exception was Hurlbutt and Chalmers' study, which failed to declare an epistemological or ontological grounding. In addition, although an appropriate design was described, Muller et al. (2003) neglected to offer a clear rationale. All studies described appropriate data collection strategies in line with their purpose, with the exception of Hurlbutt and Chalmers, who conducted an undisclosed number of interviews by email.

Sample criteria and recruitment methods were generally well described. This is with the exception of McKnight-Lizotte (2018), who failed to offer details of the recruitment process or how participants were selected. The remaining six studies outlined appropriate sampling strategies, and five of these studies provided corresponding justification for their sampling method (Muller et al., 2003; Griffith et al., 2011; Krieger et al., 2012; Baldwin & Costley, 2016; Sosnowy et al., 2018).

Six of the studies provided an explanation of an appropriate analytic approach (Muller et al., 2003; Griffith et al., 2011; Krieger et al., 2012; Baldwin & Costley, 2016; McKnight-Lizotte, 2018; Sosnowy et al., 2018). However, Hurlbutt and Chalmers failed to reference the explicit analytic approach utilised. More than one researcher was involved in the analysis for five of the studies (Muller et al., 2003; Hurlbutt & Chalmers, 2004; Griffith et al., 2011; Krieger et al., 2012; Sosnowy et al., 2018), whilst three of the studies (Muller et al., 2003; Hurlbutt & Chalmers, 2004; Krieger et al., 2012) included participants in the analysis process.

Social, physical or interpersonal contexts were described in all studies, and evidently taken into account in the interpretation process in six of the seven studies (Muller et al., 2003; Hurlbutt & Chalmers, 2004; Griffith et al., 2011; Krieger et al., 2012; McKnight-Lizotte, 2018; Sosnowy et al., 2018). Studies did not provide transparent audit trails, with the exemption of the study by Krieger et al. (2012), in which an example excerpt from a transcript was shown along with a detailed description of the decision-making process. All studies included sufficient quotes in their results sections to offer support for their interpretations.

Only two of the studies demonstrated researcher reflexivity (Hurlbutt & Chalmers, 2004; Krieger et al., 2012). This was shown in various ways such as through keeping field journals to validate findings, and acknowledging the influence of author preconceptions. A particularly good example was by Krieger et al. (2012), which highlighted the importance of the participant-researcher relationship during fieldwork: *"The development of mutual rapport was essential for conducting the interviews. The environments and researcher's intuition were important factors in achieving this. One example of how the environment influenced rapport in a positive way was that one participant who worked as a gardener could display his broad botanical knowledge during a walk through the gardens while the researcher shared observations of flora on a recent visit to a tropical rainforest".*

The reporting of ethical considerations was fairly lacking. Four studies explicitly referenced approval being granted (Krieger et al., 2012; Baldwin & Costley, 2016; McKnight-Lizotte, 2018; Sosnowy et al., 2018) and four described the consent process (Muller et al., 2003; Griffith et al., 2011; Krieger et al., 2012; McKnight-Lizotte, 2018). Only two studies sufficiently described how confidentiality and anonymity were managed or showed consideration of other possible ethical issues (Griffith et al., 2011; McKnight-Lizotte, 2018).

Each study provided evidence of the relevance of their findings. All papers linked their results well to previous research, with the exception of Muller et al. (2003) and Hurlbutt and Chalmers (2004) who failed to adequately interweave their results with past literature. However, it must be noted that literature in this area is limited, and that the aforementioned papers were the oldest studies, thus there would have been limited research to refer to at the time. Limitations were mentioned in all studies. Finally, guidance for future research was outlined in each study, with the exception of the Hurlbutt and Chalmers (2004) paper.

Table 1.3: Quality Ratings

Stage	Essential Criteria	Muller et al. (2003)	Hurlbutt & Chalmers (2004)	Griffith et al. (2011)	Krieger et al. (2012)	Baldwin & Costley (2016)	McKnight-Lizotte (2018)	Sosnowy et al. (2018)
Scope & Purpose	Clear statement of focus for research	X	X	X	X	X	X	X
	Rationale for research	X	/	X	X	X	X	X
	Questions/ Aims / Purpose	X	X	X	X	X	X	X
	Study thoroughly contextualised by existing literature	X	/	X	X	X	X	X
Design	Method/ Design Apparent	X	/	X	X	X	X	X
	Above consistent with research intent	X	/	X	X	X	X	X
	Rationale given	/	/	X	X	X	X	X
	Data collection strategy apparent	X	X	X	X	X	X	X
	Data collection strategy appropriate	X	/	X	X	X	X	X
Sample Strategy	Sample and sampling method explained	X	X	X	X	X	/	X
	Above Justified	X	/	X	X	X	/	X
	Above Appropriate	X	X	X	X	X	/	X
Analysis	Analytic approach explained	X	/	X	X	X	X	X
	Above appropriate	X	/	X	X	X	X	X
	More than one researcher involved if appropriate	X	X	X	X	/	/	X
	Participant involvement in analysis	X	X	/	X	/	/	/
Interpretation	Context described	X	X	X	X	X	X	X
	Context taken account of in interpretation	X	X	X	X	/	X	X
	Clear audit trail	/	/	/	X	/	/	/
	Data used to support interpretation	X	X	X	X	X	X	X
Reflexivity	Researcher reflexivity demonstrated	/	X	/	X	/	/	/
Ethical dimensions	Ethical approval granted	/	/	/	X	X	X	X
	Documentation of how consent was managed	X	/	X	X	/	X	/
	Documentation of how confidentiality and anonymity were managed	/	/	X	/	/	X	/
Relevance	Evidence of study relevance	X	X	X	X	X	X	X
	Links to theories and literature	/	/	X	X	X	X	X
	Limitations/weaknesses outlines	X	X	X	X	X	X	X
	Outlines further directions for research	X	/	X	X	X	X	X

Meta-Synthesis

The mapping of second-order constructs onto third-order constructs is displayed in Appendix 1.2. Five third-order interpretations concerning the employment experiences of individuals with ASD were elicited: 1) Lacking Social Skills is a Barrier to Progress, 2) Feeling Undervalued 3) Misunderstandings and the Need for Clear Communication, 4) The Desire for Informed Support and Training, and 5) Sensory Overstimulation Increases Work Stress. The content of each concept is outlined below with participant quotes presented in italics.

1) Lacking Social Skills is a Barrier to Progress

A dominant theme across all studies was the view that social difficulties were a hindrance to workplace success. It was clear that many facets of workplace interaction were a struggle for employees with ASD including reading facial expressions, deciphering meaning from tone, and determining the appropriate time to start and conclude conversations. One participant summarised the common viewpoint:

"I look at my friends who work at workplaces, and to me they're like social geniuses. I feel like somebody who's had a stroke and forgotten how to walk."
(Participant quote, page 169, Muller et al., 2003).

Employees with ASD spoke of struggling to get on with co-workers, an inability to understand social rules leading to confrontation, worries about the consequences of missing social cues, and alienation because of poor-quality interactions. An example of a negative interaction arising from a lack of awareness of social etiquette was described by the female participant below:

"I would feel like tattling when somebody wasn't using the policy. I didn't understand the unwritten social thing where you don't go tattling on your co-workers. It was very stressful to try and know what to say and what not to say and when . . . I would call them [co-workers] out on things I'd be like 'you know you're not supposed to do it that way', and they'd be like 'mind your own business'"
(Participant quote, page 17, McKnight-Lizotte, 2018).

Importantly, researchers found that participants viewed their social difficulties as detrimental to career progression. Muller et al. (2003) note that participants expressed an "*awareness that vocational success depended not only upon the ability to meet the technical requirements of the job, but upon one's ability to fit in*" (Author quote, page 169, Muller et al., 2003). This sentiment was echoed by researchers in the Griffith et al. (2011) study, who stated that participants' "*career potential had not been realized because of difficulties with social interaction"* (Author quote, page 539, Griffith et al., 2011). Even in instances in which employees with ASD were meeting the competencies of their jobs in all other areas, social shortfalls were believed to keep them from progressing. It was reported that employers valued personality as important in keeping a job, and there was a concern in some cases that if social situations were not handled properly it could lead to dismissal. Overall, there was a belief that conversing and getting on with co-workers was the most important thing in a job, as summarised by the following male participant:

"I'm very intelligent, I'm very capable, very dedicated but... like in the workplace, if you can't interact socially, you're not going to progress, so you sort of stay in a corner as a virtual nobody" (Participant quote, page 539, Griffith et al., 2011).

In addition, the majority of studies highlighted that social interactions were an obstacle to succeeding in job interviews (Muller et al., 2003; Griffith et al., 2011; Baldwin & Costley, 2016; McKnight-Lizotte, 2018; Sosnowy et al., 2018). Many participants with ASD viewed their chances of getting a job and progression opportunities as restricted because of being unable to participate well in interviews. Individuals believed that they did not know the right things to say, were unable to answer questions properly, and felt that they did not appear interested in interviews due to aspects of social communication such as inappropriate eye contact. Interviews were perceived as intimidating, as the following woman describes:

"Sometimes they throw questions at me that I don't know how to answer without making myself look bad... I know they are looking for every single flaw, like eye contact, hand position, dress. I just feel

like it's being under a microscope. And I don't like that"

(Participant quote, page 16, McKnight-Lizotte, 2018).

2) Feeling Undervalued

There was an overall sense of participants with ASD feeling underappreciated. There was widespread frustration at periods of unemployment, recurrent job losses, and being unable to gain a job in a field which utilised qualifications or expertise. Authors in the Griffith et al. (2011) study described the impact of being unable to maintain a job, explaining it could "*have profound effects on participants' sense of self-worth"* (Author quote, page 539, Griffith et al., 2011). The following female participant outlines her struggle:

"I have a degree in political science and am just trying to get a decent job with decent pay and benefits. I have cleaned cat cages, done janitorial work which is boring, boring, boring, office work, been a telemarketer which I hated, but I learned how to do public speaking, and worked in a group home on the early morning shift." (Participant quote, page 218, Hurlbutt & Chalmers, 2004).

Even when participants held a job, the overall consensus was that colleagues did not value their full potential. Baldwin & Costley (2016) proposed that employees' *"abilities and skills would often go unrecognised"* (Author quote, page 489, Baldwin & Costley, 2016). Employees with ASD believed that others failed to acknowledge their competence or intelligence, and felt they had a lack of opportunity for career advancement. Accounts from several participants illustrate this:

"I resent having people assume I'm a secretary and not know about my scientific mind." (Participant quote, page 489, Baldwin & Costley, 2016)

"We are much more competent than people think. If they would only give us the opportunities" (Participant quote, page 36, Sosnowy et al., 2018)

"The years roll by and I stumble from one job situation to another and nothing consummated into a promotion or career type move" (Participant quote, page 166, Muller et al., 2003)

"I struggled to understand what I did wrong and why my abilities were not valued when I could often manage tasks better than my colleagues" (Participant quote, page 489, Baldwin & Costley, 2016)

In addition, three studies highlighted that participants were hesitant to disclose their diagnosis (Muller et al., 2003; Krieger et al., 2012; Sosnowy et al., 2018). It may be that employees were worried about losing credibility because of the stigma they could have faced, as emphasised by the following male office worker:

"I am not ashamed to talk about being an Asperger. But as long as the word Autistic is used as an insult, I don't believe in progress after disclosure" (Participant quote, page 151, Krieger et al., 2012).

Hurlbutt & Chalmers (2004) proposed that employers must consider the advantages of hiring individuals with autism, given that employees with ASD believed they possessed traits which made them more competent than their neurotypical counterparts (Hurlbutt & Chalmers, 2004). It may be that employees with autism would feel more valued if their bosses had greater knowledge regarding their positive characteristics. This is consistent with exceptional accounts highlighting positive experiences due to the role matching employees' specific skill sets (Muller et al., 2003; Krieger et al., 2012; Sosnowy et al., 2018). Such jobs tended to have flexible working hours, minimal requirement for social skills, and emphasised technical interests; these were the type of roles participants reported being more satisfied with. The following participant was more motivated by his work because of its meaning and fit:

"My professional success can be explained in the choice of an introverted profession in a technical field and a knowledge-intensive environment" (Participant quote, page 149, Krieger et al., 2012).

3) Misunderstandings and the Need for Clear Communication

In addition to social skills, it was apparent from the review that miscommunication was a problem. A combination of comprehension difficulties of individuals with ASD, as well as unclear communication from their colleagues led to misunderstandings, and in turn negatively influenced productivity. Individuals reported struggling to understand the underlying meanings of messages, as well as difficulties processing information. When co-workers delivered vague instructions, workers would often fail to understand them. This could lead to asking excessively for clarification, or being unable to complete tasks correctly. In some instances, it could also result in unfavourable appraisals or reprimands. One man described his workplace communication woes:

"My biggest problem with that job was communication, trying to figure out, okay, what am I supposed to do here? I ended up several days with nothing to do, because I couldn't get my boss to explain to me what I needed to do with something, and he was busy with every other project. Part of the problem was that I really needed to know what to do, and every time I tried communicating with my boss, he wouldn't answer" (Participant quote, page 20, McKnight-Lizotte, 2018)

In contrast, participants also spoke of instances of positive employer communication and made suggestions about increasing clarity, such as providing instructions that include as much detail as possible. Authors in Muller et al. (2003) suggested that there is a "*preference for direct, even blunt, communication*" (Author quote, page 171, Muller et al., 2003). Participants also expressed a desire for unambiguous organisational structures and clear hierarchies. If responsibilities, rules and expectations were communicated explicitly in advance, this would increase confidence and success in the workplace. In addition, some employees with ASD discussed creative ways to aid understanding such as being shown what to do through role play, or having things written out, as the following participant describes:

"Writing out the instructions of what the supervisor wants done. That's a biggie. If he writes it out – 'this is what has to be done' – you're not wondering if there are any loose ends, which was a constant problem for me." (Participant quote, page 172, Muller et al., 2003).

4) The Desire for Informed Support and Training

Findings from the studies strongly indicated that support would be welcomed. Baldwin & Costley (2016) summarised that employees' "*require additional help if they are to realise their goals and reach their full potential in the world of work*" (Author quote, page 492, Baldwin & Costley, 2016). Where adequate support had been received, it was found to be enabling. If employees with ASD had job mentors, they tended to guide employees with tasks, whilst allowing ample time to complete them. As well as mentors, McKnight-Lizotte (2018) proposed that communication or social interventions could assist skill development. Interaction training via methods such as video guidance was well-received by their study participants:

"There were some videos that they would show us. You know, we are learning the value of knowing the customer's name...we would watch the videos and learn what they wanted us to do and how they wanted us to sell, and scripted interactions" (Participant quote, page 22, McKnight-Lizotte, 2018).

However, researchers often found that job coaching was not available, and those who did not receive support yearned for it, believing it would increase their workplace success. The following woman made this plea:

"I like the idea of having job mentors. This would be an individual already established in a career who could use his or her creative energy to guide and develop the creative talents of an autistic person and lead them to a satisfying job. One person can make a difference in how successful the person with autism will be" (Participant quote, page 219, Hurlbutt & Chalmers, 2004).

In addition, there was a desire for help in the process of gaining a job. Studies highlighted that support services should be more widely available to assist with CV writing, interviewing, social interactions, and obtaining meaningful jobs that matched skill sets and interests. Sosnowy et al. (2018) surmised that most participants *"needed help in securing employment and would need accommodations in order to keep a job"* (Author quote, page 36, Sosnowy et al., 2018). Accounts from those who had received support from employment services had found them to be unhelpful, largely due to lack of knowledge:

"I have been trying to get support because I've been to the Job Centre...but because it's not a physical problem really, she can't help me. So, if you're in a wheelchair, it's visible, isn't it? But because I'm intelligent, and I think most people who have Asperger's are intelligent, they don't expect you to have problems with things. It's so stupid. Employers on the whole don't know much about

autism, and autism is a very complicated impairment." (Participant quote, page 540, Griffith et al., 2011).

Correspondingly, several researchers noted participants' disappointment with lack of knowledge around ASD and a desire for colleagues and employers to be educated on ASD via training programmes (Muller et al., 2003; Hurlbutt & Chalmers, 2004; Griffith et al., 2011). This finding highlights the wish for employers to also receive training to aid their understanding of the condition.

5) Sensory Overstimulation Increases Work Stress

Concerns were also raised about excessive sensory stimulation in the working environment. Anxiety-provoking sensory overload was reported to be caused by noisy surroundings, crowds, and unexpected touching. Participants with ASD believed they were much more sensitive to this than their peers in the workplace. In some instances, if sensory stimulation became too much, it could lead to becoming cognitively overwhelmed or 'meltdowns':

"Our pharmacy is in a busy shopping centre – the noise and activity is extreme. I have a meltdown (carefully hidden as much as possible) every week on average" (Participant quote, page 489, Baldwin & Costley, 2016).

Likewise, several studies highlighted the need for quieter environments to increase work success (Muller et al., 2003; Krieger et al., 2012; Sosnowy et al., 2018). One participant describes how her setting with little sensory distraction was enabling:

"Working behind a window in the post office protected me" (Participant quote, page 151, Krieger et al., 2012).

The authors of the Krieger et al. (2012) paper suggest that *"A clearly structured workplace with few distractions and reduced noise to promote concentration and calm was essential"* (Author quote, page 151, Krieger et al., 2012).

Discussion

This review synthesised the available qualitative research regarding employment experiences of individuals with ASD. Results indicated that participants often felt undervalued in their place of work. Social deficits characteristic of autism were perceived as obstructing career development. Likewise, miscommunication was problematic, with employees expressing a desire for clarity when receiving information. Excessive sensory stimulation in work settings was reported to be emotionally taxing. Finally, workplace support was found be helpful although it was rarely available.

The finding that social difficulties hinder progression adds a new dimension to the current literature. Research has shown that social challenges impact engagement in employee discussions and team exercises (Richards, 2012). It has been suggested that workers with ASD have a higher tendency to become angry, can be viewed as arrogant, and struggle with assertiveness or asking for assistance (Meyer, 2001). This could explain breakdowns in working relationships, and may act as a barrier to progress. However, Roux et al. (2013) proposed that young people with ASD who have better conversational abilities have better employment outcomes (Roux et al., 2013); suggesting success may depend on individual skills. In addition, the qualitative review highlighted that poor social skills could act as a barrier to gaining employment, particularly due to difficulties with job interviews. This is consistent with research showing that interviewees with ASD may interrupt discussions and struggle to build reciprocity with interviewers (Morgan et al., 2014).

Likewise, miscommunication was a problem within the workplace. In line with this view, Biggs et al. (2010) propose that employers are often unwilling to supervise employees with conditions requiring additional support, due to having to provide extra assistance with instructions (Biggs et al., 2010). The current review highlighted the importance of clear communication, consistent with the notion that employees with ASD require transparent, comprehensive, and linear instructions (Fast, 2004). Accounts from managers also highlight that successful supervision relies on being direct when conversing with employees who have ASD (Hagner & Cooney, 2005).

Feeling undervalued was a major theme from the review, consistent with outcome data reporting unemployment, underemployment, and poor job security for people with ASD (Howlin et al., 2004). Review findings correspond with reports from parents which highlight that their children with autism are often directed towards underpaid jobs or careers they may be overqualified for (Cheak-Zamora et al., 2015). Research has suggested that some bosses are intolerant of employees with ASD (Grandin & Duffy, 2004), and there is inconsistent management by employers of condition disclosure (Meyer, 2001); attitudes which may exacerbate feelings of low worth. On the contrary, some research has indicated that some workers with autism have been evaluated highly by supervisors (Hagner & Cooney, 2005). Thus, whether employees with ASD feel appreciated could depend on employer attitudes or indeed job suitability or support received, as described in the current review.

Studies from the UK, USA, and Australia in the current review highlighted that appropriate support was often unavailable. This is consistent with UK estimates that only 10% of individuals with ASD receive support for interviews, and only 22% gain specialist support when in a job (Beardon & Edmonds, 2007). Likewise, Australian figures show that 74% of employed adults with high-functioning ASD do not receive support at work (Autism Spectrum Australia, 2013). In addition, only 12% of adults with ASD receive supported employment in the US (Taylor & Seltzer, 2011). Unhelpful employment service experiences were uncovered in the review, consistent with evidence suggesting that employment specialists have limited understanding of the career potential of adults with high-functioning autism (Fast, 2004). Perspectives from the synthesis outlined that appropriate support could be enabling, corresponding with perspectives of supervisors who found greater success when accommodations were put in place (Hagner & Cooney, 2005).

Links between sensory modulation and emotional disturbances in ASD are well established (Pfeiffer et al., 2005). The evidence in the current review highlighted that disposition to sensory stress could be inhibiting in work environments. The findings are consistent with the account that employees with high-functioning ASD find it hard to cope with workplace stimuli including office conversations and flickering lights (Grandin & Duffy, 2004). Sensory difficulties at work are common for adults with high-functioning ASD (Beardon & Edmonds, 2007), thus, coupled with review findings, environmental adjustments may facilitate employees with ASD.

Limitations

Unpublished literature was excluded; however publication bias may have meant that relevant data was missed. Likewise, in relation to the search process, qualitative systematic reviews are weakened by poor electronic indexing of qualitative literature, often making studies difficult to detect (Centre for Reviews and Dissemination, 2009). To increase inclusivity, the current review did not exclude on the basis of quality ratings, although it is possible that methodologically flawed studies may have influenced outcomes. However, themes that transpired from the methodologically weaker studies were comparable to the stronger papers. The search included publications from the year 2000 onwards, however this particular year was selected arbitrarily. The synthesis incorporated a range of epistemologies and methodologies, and the analysis was deemed appropriate for encompassing the diverse studies (Campbell et al., 2003). However there remains debate about the suitability of meta-ethnography in synthesising numerous qualitative methodologies (Dixon-Woods et al., 2004), with some claiming it should be used solely to synthesise studies within one paradigm (Jensen & Allen, 1996).

France, Cunningham, et al., (2019) outline standards for reporting literature using meta-ethnography, and this guidance was considered in the current review (France, Cunningham, et al., 2019). However word count limits meant it was not possible to report every aspect of the meta-ethnography process in detail. Appendix 1.3 describes the reporting criteria met and not met in the current review. In relation to the synthesis method, meta-ethnography is an interpretative approach which combines participant findings and author interpretations to produce new meaning (Ring et al., 2011). It is acknowledged that this synthesis method generates findings which are removed from individuals' lived experiences, and that there are challenges in maintaining sufficient familiarity with the original studies (Campbell et al., 2011).

Word count limits imposed by journal publishers could prohibit researchers from reporting certain details in their articles. This could have led to important methodological information being excluded from publications, in turn affecting quality ratings. The vast majority of papers did not include an audit trail, thus it is impossible to know how interpretations were developed. The review included studies which investigated employment, and only qualitative data relating to employment experiences were extracted. However, the focus of each study differed, with some studies exploring additional experiences of living with high-functioning autism outside employment (Griffith et al., 2011; Baldwin & Costley, 2016; Sosnowy et al., 2018). Studies focussing solely on employment may have provided more rich data pertinent to the review.

In addition, there are aspects of studies included in the review that are not explored in depth, such as career ambitions or family circumstances. Participants' work history and current employment status differed in each study, and this may have influenced the detail of accounts. Likewise, participant demographics varied in each study. For instance, Griffith et al. (2011) focused on individuals in middle adulthood, whilst Sosnowy et al. (2018) recruited younger participants. It is not possible to know whether perspectives were influenced by age or length of experience. There may also be gender bias as the majority of studies included more males. This is with the exception of the study by Baldwin & Costley (2016), which exclusively analysed females. Gender differences in employment may have been useful to explore, given ASD can be expressed differently in males and females (Krieser & White, 2014). Likewise, the review only included individuals from western countries, and research has shown that cultural differences can impact condition perceptions (Matson et al., 2017). The majority of included studies relied on a self-reported diagnosis of ASD, as opposed to formal confirmation from professionals; therefore it is not possible to verify the reliability of these reports. Furthermore, the review only represents the viewpoints of high-functioning autistic people, and neglects individuals with more complex needs.

Implications and Conclusions

It would be beneficial if employers and co-workers had a better understanding of ASD and the capabilities of employees with ASD, with scope for awareness training to facilitate this. Another key proposal would be to provide more support to employees with ASD. Employment services could try to ensure jobs match employees’ interests and qualifications, as well as providing training on social skills and job interviews. Likewise, ongoing support and accommodations, such as tailored instructions or environmental adjustments, could be established in the workplace. Future research should focus on refining appropriate vocational interventions by seeking perspectives of employees with autism, their employers, and support professionals. Further investigations should also consider the influence of culture, age, gender and ASD severity on employment experiences.

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Chapter Two: Major Research Project

A Comparison of the Content and Nature of Worries of Young People with and without Autism Spectrum Disorder as they Transition out of School

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Plain English Summary

Background: A time known as transition, when a young person is getting ready to leave school, is particularly important. A previous study has shown that worries of young adults with intellectual disabilities (ID) are different from young adults without IDs after transition, because of different life experiences (Forte et al., 2011). This research also found that young adults with IDs were more anxious, their worries caused them more distress, and they ruminated more over their worries. Another study looked at worries in adolescents with and without IDs as they moved on from school, and also found that concerns were different due to variations in life experiences (Young et al., 2016). There is not much research looking into the worries of adolescents with Autism Spectrum Disorder (ASD). It would be useful to explore the concerns of adolescents with ASD during transition to help us find out if support should be introduced in schools, which could help improve mental wellbeing.

Methods: Twenty-two participants with ASD and twenty-two participants without ASD from secondary schools in the Scottish Highlands took part. Participants were all aged 16-18. Participants were interviewed using an altered version of the 'Worry Interview', which was used in the Forte et al. (2011) study. This involved being shown various pictures representing 'worry topics', which included subjects such as school, failure, and change, amongst others. Participants were asked whether or not each topic was something they worried about, and if so, they were asked to explain why. Participants indicated what their 4 biggest worries were, and stated how much distress each worry caused, and how much they ruminated over each worry. Participants also completed a questionnaire to measure their anxiety.

Main Findings and Conclusions: Adolescents with autism were more worried about change, friendship, loneliness, school, and sensory concerns. Adolescents without autism were more worried about failure, work, health, and money. There were differences in the content of worries between adolescents with and without ASD, which could reflect different life experiences. For example, on the topic of change, participants with autism worried about unexpected changes to plans or routines, whilst adolescents without autism worried more about moving away. Also, regarding friendship, participants with autism worried more about finding socialising difficult, whilst participants without autism worried more about losing contact with friends after school. Participants with autism did not ruminate more over their worries. However, their worries did cause them more distress, and they were a lot more anxious. It is important that professionals talk about worries with pupils leaving school, to find out the cause of concerns and possibly help problem-solve them. This could help reduce distress and anxiety, and make the transition process easier. The Worry Interview could be used by professionals to initiate conversations about concerns with young people.

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Abstract

Background: Transition from secondary school is an essential time in development. For adolescents with Autism Spectrum Disorders (ASD) it can be particularly challenging, with studies highlighting low employment rates, reduced participation in further education, and higher levels of isolation. Previous research has shown that worries held by adolescents with intellectual disabilities (ID) differ from their non-ID peers. However, the worries of adolescents with autism are under-researched. This project aimed to explore the content and impact of worries of young people with autism at the stage of transition from school.

Methods: Twenty-two participants with ASD and twenty-two participants without ASD, aged 16 to 18, were recruited from mainstream schools in the Scottish Highlands. Participants completed a 'Worry Interview'; a semi-structured interview modified from a previous study investigating worries in young people with IDs. The participants' levels of rumination and distress about their most salient worries were measured. An anxiety scale was also completed.

Results: Content analysis highlighted differences between the two groups' worries. Participants with ASD were more concerned about change and friendship, whereas those without ASD had more salient worries about subjects like work and money. The ASD group were significantly more distressed by their worries, and were also significantly more anxious than the control group.

Conclusions: Key differences in the nature of worries between the two groups were highlighted. Consideration should be given to the specific concerns of pupils as they approach leaving school. This could ease the transition process by reducing anxiety and distress.

Introduction

Borkovec (1983) describes worry as relatively uncontrollable thoughts and images regarding potential negative outcomes (Borkovec, 1983). ‘Normal’ amounts of worry are accepted as adaptive (Wells, 1995). Worries have been linked to problem-solving (Szabo & Lovibond, 2002), preparation for action, decision making, and motivation (Floyd et al., 2005). However, chronic worry plays a major role in anxiety disorder maintenance (Holaway et al., 2006). Similarly, research has shown a link between rumination and psychological distress (Morrison and O’Connor, 2005). In addition, a recent meta-analysis investigated intolerance of uncertainty, defined as the incapacity to endure an aversive response triggered by the absence of sufficient information, and found it to be strongly associated with worry and anxiety in young people (Osmanagaoglu et al., 2018). Likewise, a longitudinal study of adolescents found a bidirectional relationship between worry and intolerance of uncertainty (Dugas et al., 2012). The influence of worry suggests it is a significant characteristic of mental wellbeing.

Worry content varies with sociodemographic factors, such as marital status, educational attainment, gender, and age. A UK survey found that those aged 55-74 worried less about relationships, housing, and work, compared to those aged 16-24 (Lindesay et al., 2006). As well as content, the intensity and frequency of worry can influence mental wellbeing. Worry intensity differentiates non-pathological worry from pathological worry (Cartwright-Hatton, 2006), and anxiety has found to be positively correlated with rumination and distress (Forte et al., 2011). Reasons why these links exist are uncertain. One theory suggests that pathological worriers experience more distress as they cannot problem-solve their worries (Szabo & Lovibond, 2004). Other research suggests that metacognitive beliefs (such as worry is harmful) could be linked with distress in adults (Cook et al., 2015). Beliefs about worry have also found to be predictive of anxiety in children (Theilsch et al., 2015). One investigation analysed thoughts in adults with high-functioning autism whilst they were anxious, and found that self-focus, rumination lasting over 10 minutes, and worries about everyday events were associated with anxiety (Hare et al., 2015).

Autism Spectrum Disorders (ASD) refer to a set of heterogeneous neurodevelopmental conditions characterised by communication and social interaction impairments, restricted interests, and repetitive behaviours (APA, 2013). ASD is more prevalent in males than females (Halladay et al., 2015). Research into worry in adolescents with ASD is underexplored, with only a small number of studies revealing findings relating to the content of concerns. A small focus group study aimed to increase understanding of anxiety in ASD by gathering the views of four boys aged 10-12 with high-functioning ASD, and their parents. The children's themes surrounded change in routine, sensory triggers, social worries, and bullying (Ozsivadjian et al., 2012). Another interview study asked one female and eleven male adolescents about their worries at school. Themes surrounding friendship, reputation, and coping with unpredictability emerged (Cage et al., 2016). The lack of comprehensive research exploring the concerns of young people with ASD warrants the need for further investigation.

Worry content has been explored in more depth previously in those with intellectual disabilities (ID). Forte et al., (2011) researched participants with and without an ID as they transitioned out of college. The researchers employed a 'Worry Interview'; a semi-structured interview whereby participants were shown pictures of relevant 'worry topics' to stimulate dialogue about their concerns. Content analysis revealed differences in worry content between the two groups, reflecting differences in their past experiences. For example, a prominent worry exclusive to the ID group concerned being bullied, due to previous victimisation (Forte et al., 2011). A follow-up study employed the same methods and found differing worry content in non-ID and ID participants as they left school (Young et al., 2016). This method has been evidenced to effectively facilitate relevant discussions and generate rich findings surrounding worries in young people with and without an ID. The accessible nature and structured facilitation of the 'Worry Interview' also has the potential to be applied to adolescents with ASD to explore concerns, and therefore could extend the previous findings in the literature.

It is estimated that 40% of children with ASD meet the diagnostic criteria for an anxiety disorder (van Steensel et al., 2011), and up to 84% suffer from impairing, sub-clinical anxiety symptoms (White et al., 2009). Prevalence rates of anxiety disorders in ASD are considerably higher compared to children with IDs (Gillott et al., 2001), and typically developing children (Kerns and Kendall, 2012). Likewise, anxiety levels of youths with autism are generally much higher than their typically developing and clinically referred peers (van Steensel & Heeman, 2017). Reasons why young people with ASD are more inclined to develop anxiety are speculative. Social skill deficits and psychological hyperarousal leading to social anxiety is one proposed explanation (Bellini, 2006). Another suggestion is that ASD characteristics (such as repetitive behaviours) and anxiety exacerbate each other (Wood & Gadow, 2010). It has also been theorised that youths with autism have a neurobiological predisposition to ASD-specific difficulties, which, coupled with environmental factors (such as bullying), can contribute to anxiety (van Steensel et al., 2014). Anxiety-related difficulties are among the most common presenting problems for young people with ASD, according to teachers (Waddington and Reed, 2006). Studies have shown that these issues impact on academic achievement and social functioning (Bellini, 2004; Sze and Wood, 2007). However viewpoints of adolescents with autism are often unheard in research (Pellicano et al., 2014).

The transition from high school can be particularly stressful. It signifies a time of increased independence, often involving career or further education pursuits (Arnett, 2000). For adolescents with ASD, transitioning can be particularly challenging. In the UK, only 16% of adults with autism are in full-time paid employment (National Autistic Society, 2016). Furthermore, post-secondary education attendance is lower (Newman et al., 2011). Isolation is common, as youths with ASD often have reduced social contact post-school (Howlin et al., 2013). For young people with ASD, transition planning is important for improving post-school outcomes (Wilczynski, Trammell & Clarke, 2013). However, a review of transition planning programs for young people with ASD showed that all were unable to predict effective transition to employment (Westbrook et al., 2015). Given the difficulties faced, further research is needed to understand the impact and nature of worries of school leavers with ASD, which could inform appropriate interventions and aid mental wellbeing during transition.

Research Aims and Questions

The project is the first to employ the structured approach of the ‘Worry Interview’ to explore the concerns of adolescents with ASD; a vastly under-researched area. Therefore it is considered an exploratory study. It aimed to investigate whether there were differences in the content and nature of worries between an ASD and control group of adolescents as they approached transition out of school. The research questions were:

A. Are there differences between the ASD and non-ASD groups in terms of:

i) The types of worries described

ii) Rumination in relation to the worries

iii) Distress caused by the worries

iv) Anxiety

B. Are there positive correlations within groups in terms of:

i) Anxiety and distress

ii) Rumination and distress

iii) Anxiety and rumination

Methods

Participants

Twenty-two young people with high-functioning ASD and twenty-two typically developing adolescents were recruited from mainstream secondary schools in the Scottish Highlands. All participants were aged between 16 and 18. Adolescents can choose to leave school at 16, thus all participants were approaching transition. Participants were only included if they were English speaking and able to provide informed consent. Participants were excluded if they had an intellectual disability, or if they had a significant sensory or physical impairment that would hinder task performance.

Design

The project employed a mixed-methods design. A qualitative between-subjects approach explored and compared the content and nature of worries. A between-subjects quantitative method analysed differences in the impact of worry between both groups in terms of anxiety, rumination, and distress experienced. A within-subjects quantitative approach investigated correlations between anxiety, rumination, and distress scores within both groups. A mixed-methods approach may offer greater value than a well-conducted qualitative study in that it provides structured facilitation of the discussion of sensitive topics. This may be particularly relevant for adolescents with autism, with research indicating that young people with ASD have difficulties in initiating conversations (Preece and Jordan, 2010), as well as answering abstract questions (Beresford et al., 2004).

Measures and Interview

The measures and worry interview are described in the order they were administered.

1) A background information sheet gathered information on participant characteristics including gender, age, and location. The Carstairs Index (Carstairs and Morris, 1990) determined socio-

economic status, which ranks postcodes on a 7 point ‘DEPCAT’ scale from most affluent (1) to most deprived (7), based on recent census data.

2) To investigate the content and salience of participants’ worries, the ‘Worry Interview’ was administered. The tool was developed by Forte et al. (2011), in their study investigating worries in college students with and without an ID. Young et al. (2016) used an adapted version with school pupils with ID. The semi-structured interview uses graphic representations of ‘worry topics’ to stimulate a dialogue about participants’ concerns. Seventeen topics were included: family, friendship, school, further education, bullying, loneliness, relationships, money, work, appearance, home, decisions, failure, health, death, sensory, and change. The worry topics were chosen after thorough piloting, as described in the ‘Development Phase’ section. Participants were shown a photograph of a worry topic (such as a picture representing money). Participants were then asked, ‘What is this a picture of?’, and ‘What does this picture make you think of?’ Participants were given time to discuss each image, then were asked to assign them to either a mat which said ‘no, this is not a worry for me just now’, or ‘yes, this is a worry for me just now’. If the participant indicated that a subject was a worry, the researcher asked them to talk about it. To be counted as a worry, the participant had to describe a related example. To eliminate order effects, worry topics were presented in a randomised order, using three permutations assigned across groups. After the participants had sorted all of the items, they were asked if they had any other worries that hadn’t been discussed. Topics assigned to the ‘no’ pile were discarded, and the participant was then asked follow-up questions. To gauge distress and rumination levels for salient worries, participants were prompted to rate on a 3-point visual analogue scale how upset thinking about the subject made them feel (a little, quite, a lot), and how much they currently worried about the subject (sometimes, often, always). Lastly, participants were shown four boxes of decreasing size, and asked to select their 4 most prominent worries from the yes pile and rank them from 1-4 (biggest to smallest). Worry Interview materials are displayed in Appendix 2.1, 2.2, and 2.3.

3) The Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID) was administered to measure participants' anxiety levels. It comprises 27 questions which investigate worries, fears, and physiological symptoms over the past week. For each item, participants were asked to respond if they had 'never felt like this', 'sometimes felt like this' or 'always felt like this/ felt like this a lot'. Responses were correspondingly tallied as 0, 1, or 2, yielding a final score from a maximum of 54. The questionnaire has good test-retest reliability (r=0.95), internal consistency (a = 0.96), and is reasonably correlated with the Beck Anxiety Inventory (ρ=0.75) (Mindham & Espie, 2003). The GAS-ID is shown in Appendix 2.4.
4) The two-subtest form of the Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II; Wechsler, 2011) was used to provide a measure of intellectual functioning. The two-subtest version includes "Vocabulary" and "Matrix Reasoning" to yield an overall estimate of cognitive ability. Test-retest reliability correlations are adequate for children completing both the Vocabulary (r=0.9) and Matrix Reasoning (r=0.79) subtests.

Procedure

The researcher contacted head teachers to request permission to conduct the project. The researcher then issued study information sheets to teachers from schools opting in. Teachers approached eligible pupils and handed them an information sheet. After reading the information, participants deciding to take part returned a slip, informed their teacher or contacted the researcher. Following this, the researcher arranged a suitable time to meet with volunteers. All students wishing to take part completed a consent form prior to participation. The information sheet and consent form are shown in Appendices 2.5 and 2.6. Meetings were in a private room at the participant's school. Sessions lasted around 50 minutes. The cognitive assessment includes right or wrong answers. Consequently, it was administered last, to avoid influencing the participants' free responses on the Worry Interview. To enhance engagement, participants were offered breaks when needed, and had the option to meet over two days if required. The interviews were audio recorded and transcribed verbatim.

Development Phase

A development phase of the Worry Interview was conducted with the first two volunteers with ASD. The purpose of this phase was to establish whether any changes needed to be made to previous versions, for applicability to an adolescent ASD population. The development phase included the 15 topics carefully drawn from the wider literature by Young et al. (2016), as these topics had already proven to be pertinent concerns to adolescents leaving school.

Regarding incorporating ASD-specific topics, the researcher scoped the literature on the worries of young people with ASD. Two relevant studies covered the content of young people’s concerns. One small focus group study yielded comments pertaining to change in routine, sensory triggers (such as shouting), social worries, and bullying (Ozsivadjian et al., 2012). Another interview study with ASD adolescents found themes relating to social concerns, school challenges, and unpredictability. Authors noted that one participant described noise as a concern (Cage et al., 2016).

Based on the findings, and accounting for overlapping themes, two new topics were added to the worry interview: change and sensory. All 17 topics were trialled with the first two volunteers with ASD, and were found to be relevant. Therefore the topics of change and sensory were kept in the final version. No further amendments were made. The first two participants with ASD who completed the study during the development phase were included in the overall findings, given that the worry interview and the study procedure they completed was identical to the procedure employed thereafter.

Sample Size Justification

The study was exploratory. However, the between-subjects quantitative component employed the same methodology used by Forte et al., (2011). Using independent t-tests, Forte et al., (2011) found a large effect size of 1.38 for the differences between distress scores of young people with and without IDs. A medium to large effect size of 0.65 was found for the differences between rumination scores. Thus, a sample size calculation was carried out using this data. The calculations showed that 30 subjects per group would be needed to find a significant difference between rumination scores, and 8 participants in each group would be needed to find a difference in distress scores. Both calculations were based on a power of 0.8 at an alpha level of 0.05 (one-tailed).

Ethical Approval

Ethical approval was granted by the University of Glasgow College of Medical, Veterinary and Life Sciences (MVLS) Ethics Committee. Appendix 2.7 consists of the ethical approval letter. Approval was also gained from the Highland Council to conduct the research in schools covered by the area.

Results

Sample

Twenty-two young people with ASD and twenty-two typically developing young people took part. A full dataset was obtained for all participants. This is with the exception of one male in the ASD group who refused to complete the WASI-II. The participant was included in the final study. Average IQ for the ASD group was calculated in the absence of this individual's score.

Demographic details are outlined in Table 2.1. The groups were fairly well matched in terms of age, socio-economic status, gender, and IQ. Both groups had slightly more males. Two of the biological females in the ASD group did not identify with a particular gender. The mean age of the control group was 17.4, and the ASD group was 17.0. The mean IQ was slightly below average in the control group, and slightly above average in the ASD group. All participants lived in the Highlands of Scotland. The average deprivation score was around 3 for both groups, meaning participants tended to live in areas of average wealth.

Table 2.1: Participant Demographics

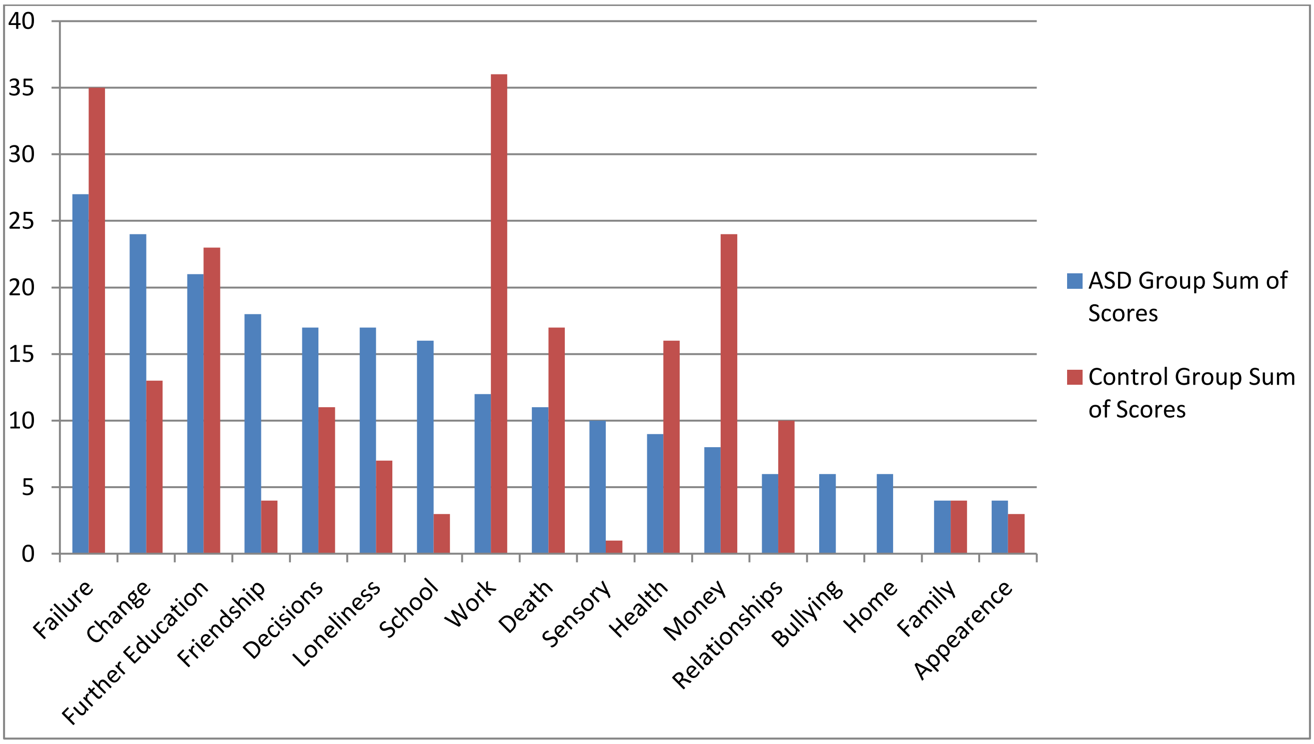
Group	Number	Age	Male: Female Biological Gender Ratio	Mean DEPCAT score	Mean IQ from WASI-II
ASD	22	Mean = 17.0 SD = 0.6 Range = 2.0 Min = 16.0 Max = 18.0	13:9*	Mean = 2.8 SD = 0.9 Range = 3 Min = 1 Max = 4	Mean = 103.7 SD = 14.4 Range = 51 Min = 74 Max = 125
Control	22	Mean = 17.4 SD = 0.6 Range = 1.9 Min = 16.3 Max = 18.2	12:10	Mean = 3.1 SD = 0.9 Range = 4 Min = 1 Max = 5	Mean = 97.0 SD = 12.5 Range = 45 Min = 78 Max = 123

*Two of the 9 biological female participants did not identify with being either gender.

Worry Salience

After assessing all worry topics, participants selected their four 'biggest' worries. A score of 4 was assigned to the most salient worry; a score of 3 was assigned to the second most salient worry, and so forth. The most salient worries for each group were established by calculating the sums of scores. The results are illustrated in Figure 2.1, in decreasing order of salience for the ASD group.

Figure 2.1: Salience of Worries



There were several differences in the salience of certain worries between the groups. The ASD group were markedly more worried about change, friendship, loneliness, school, and sensory concerns than the control group. Conversely, the control group were notably more worried about failure, work, health, and money.

Worry Content

Worry interview transcriptions underwent content analysis (Strauss, 1987). This procedure involved the researcher identifying the types of worries that emerged from the transcripts in relation to each topic, and then developing groups of categories which reflected the views expressed. An independent rater was asked to assign the participants’ worries for each topic area into the categories developed, and 100% inter-rater agreement was obtained.

Table 2.2 outlines the most common worry by group for each topic. Further worry content is shown in Appendices 2.8 and 2.9. Worry content for topics in which the salience differed between the two groups, is described in greater detail below. The way participants talked about their worries are also described below, illustrated with quotes.

Table 2.2: Most Common Worry Content

Worry Topic	ASD Group: Most Common Worry Content	No. of Participants Worried (% per group)	Control Group: Most Common Worry Content	No of Participants Worried (% per group)
Failure	Failing exams	13 (59.1%)	Failing exams	11 (50%)
Change	Unexpected changes to plans or routine	7 (31.8%)	Moving away	3 (13.6%)
Further Education	Being in a different and less familiar environment	6 (27.3%)	Getting a place at college/university	7 (31.8%)
Friendship	Finding socialising difficult	7 (31.8%)	*No main theme emerged*	*N/A*
Decisions	Making any type of decision (non-specific) Future consequences of my decisions (generally)	10 (45.5%) 10 (45.5%)	Choosing further education course	8 (36.4%)
Loneliness	Not being included socially	3 (13.6%)	Losing friends	2 (9.1%)
School	Exams Coursework	5 (22.7%) 5 (22.7%)	Exams Coursework	3 (13.6%) 3 (13.6%)
Work	Conversing with other people in a work setting	5 (22.7%)	Won't be able to get a job	6 (27.3%)
Death	The death of people close to me	9 (40.9%)	The death of people close to me	7 (31.8%)
Sensory	Not coping well with noise	9 (40.9%)	*No main theme emerged*	*N/A*
Health	Own physical health condition	6 (27.3%)	Own physical health condition	3 (13.6%)
Money	Not having enough money in future	6 (27.3%)	Not having enough money in future	10 (45.5%)
Relationships	Social skills required for a relationship	5 (22.7%)	Being alone in future	2 (9.1%)
Bullying	Attitudes of others towards bullying	3 (13.6%)	People close to me being bullied	2 (9.1%)
Home	Family arguments	3 (13.6%)	Moving out	3 (13.6%)
Family	Family members' general happiness and wellbeing	3 (13.6%)	Not keeping in touch with family	3 (13.6%)
Appearance	My eating habits	2 (9.1%)	Others judging me for the way I look	4 (18.2%)

Change

Change was the second most salient worry in the ASD group. Most who talked about this type of worry, mentioned changes to their plans or routine:

> *"I don't like change, especially a change in routine. If I'm supposed to be going into town, say we're going shopping on Sunday at 3 in the afternoon. If that suddenly changes and we have to go shopping at like 4 or 5, it's not going to go down well with me. Especially because if I'm doing anything else, I have to plan it all in accordance."*
>
> (Female from the ASD group).

By contrast, change was less salient (7th) for the non-ASD group. Those who mentioned change expressed a different concern, with the majority describing worries about major change in their lives like moving away from home:

> *"The leaving home thing, especially for people just moving out, it's completely new. Never been away before so I guess that's part of it; just like adapting I guess to the new parts of it."*
>
> (Female from the Control group)

Friendship

Friendship was the 4th most prominent worry for the ASD group. They talked about finding socialising difficult:

> *"It's like can I make friends? Or what happens if I have the wrong facial expression? Or my tone is wrong? Or eye contact? I have learned one thing that's really good and that's if you look just below the eyes or at people's noses, it tricks them into thinking that you're making eye contact. But for the most part I can't make eye contact, so are they going to think that I'm not being sincere enough in a friendship if I don't do that?"*
>
> (Female from the ASD group).

Only one participant in the non-ASD group worried about friendship, and they were mainly concerned about losing touch with friends after finishing school:

> *"Well, leaving school I'm going to lose contact with a lot of people. So it's going to be harder to hold friends, and then of course there's the issue of making new friends when you move to a new place."* (Male from the Control Group)

Loneliness

Loneliness was also a notable concern for those in the ASD group. It was their 6th most salient worry and was largely about being socially excluded:

> *"When like you don't know how to get involved in something. Sometimes people think I want to be alone but I don't, but I don't know how to explain that to them."*
>
> (Female from ASD group).

The non-ASD participants were less concerned about loneliness. However, those who did worry about loneliness were anxious about losing friends:

> *"Just the fact that anyone can turn on you and you could be in a close group of friends, and suddenly they put you out of it."* (Male from Control Group)

School

School was the 7th most salient worry for those in the ASD group. Worries surrounding exams and coursework were most common:

> *"I quite enjoy going to school, what I don't enjoy is exams. They do horribly stress me out."*
>
> (Male from the ASD group).

Likewise, coursework and exams were common themes for non-ASD participants:

> *"Exams. Stressful. We're sitting Highers and they're really hard."*
> (Female from the Control Group).

Sensory

Participants with ASD described sensory concerns, and difficulty coping with noise in particular:

> *"That is one of the hardest things for me. At school and at home because I can't cope if someone has the TV or radio on in the background. But then that's not fair to them, they can do what they want. Also, it makes me worried to go to people's houses. They might have noises that I can't cope with and then I won't be able to just tell them to stop it because I can't do that. It makes me really anxious and I start crying and having like a meltdown thing."* (Female from ASD Group).

Non-ASD participants had fewer and more diffuse sensory concerns, including losing vision and headaches. One participant described being unable to study when others were talking:

> *"I quite often find that if everybody's talking it gets quite frustrating because you're trying to study, you're trying to do something and then everybody won't shut up."*
> (Male from Control Group).

Failure

Failure was a prominent concern for both groups. It was the most salient worry for participants with ASD, and second most salient for the non-ASD group. Both groups were most worried about failing exams:

> *"Potential grades in exams. I'm not the best in things like Maths or Geography, so I worry I might fail in these exams. It would mean I wouldn't have the qualifications".*
> (Male from ASD Group)

> *"If you fail your exams, that's you done. Well you're told. You're always getting it shouted in your ears 'You've got to pass, you've got to pass', so when you're sitting in there it's 'You're going to fail, you're going to fail'".* (Male from Control Group).

Work

Work was the 8th most salient worry for those in the ASD group and the participants were anxious about how they would manage the social demands of the workplace:

> *"With the social thing, I can't look people in the eye for long enough and I'm not very good at talking to people. So that probably hinders the whole 'Oh you have to be really nice to people' thing, and I can't do that. I can't fake being nice. If I don't like you, I don't like you, and I'll just try to ignore you. But probably I'll just try to force myself to do it because I'm getting paid for it at the end of the day."* (Female from ASD Group).

By contrast, work was the most salient worry for those in the non-ASD group. The most common fear was about being unable to get a job:

> *"I don't want to be unemployed my whole life.*" (Male from Control Group).

Health

Individuals with ASD were worried about both their physical and mental health:

> *"Definitely a worry because I get ill quite frequently. I have stomach issues that play up whenever I'm stressed which is not good. My mental and physical health both worry me. With exams everyone is stressed and my anxiety just seems to go up like that. Just rockets up."*
> (Male from ASD Group).

While health worries were notably higher in the non-ASD group, they were usually concerned about their physical health:

> *"My health conditions. I think it's just not being at a constant stable level for me personally."*
> (Female from Control Group)

Money

Common worries regarding money for the ASD group were about not having enough money in future:

> *"If you end up in debt you might not have enough money to live or anything like that."*
> (Male from ASD Group)

The non-ASD group were more concerned about money and it was their 3rd most salient worry. They were also worried about not having enough money in the future:

> *"Yeah I do worry a wee bit about it, with like saving up to go to Uni and pay for rent or whatever, stuff like that. Yeah I do worry about that."*
> (Female in Control Group)

Between Group Comparisons

Descriptive statistics for rumination, distress, and anxiety scores for both groups are shown in Table 2.3. The distribution of rumination, distress, and anxiety scores for each group were explored to inform appropriate statistical tests. Normality was gauged through visual exploration of data plots, as well as via the Shapiro-Wilk test. Rumination, distress, and anxiety scores were normally distributed for the non-ASD group. However, only anxiety scores were normally distributed for the ASD group, with rumination and distress non-normally distributed. Consequently, both parametric and non-parametric tests were employed.

Table 2.3: Rumination, Distress, and Anxiety Scores Descriptive Statistics

Descriptive Data														
	N		Mean		Median		Min		Max		Interquartile Range		Standard Deviation	
	ASD	Non-ASD	ASD	Non-ASD	ASD	Non-ASD	ASD	Non-ASD	ASD	Non-ASD	ASD	Non-ASD	ASD	Non-ASD
Rumination	22	22	8.0	7.3	9	7	2	2	12	12	6	5	3.0	3.0
Distress	22	22	8.6	6.6	10	7	3	1	12	11	5	5	2.8	2.9
Anxiety	22	22	26.1	17.9	25	19	11	6	48	30	11	14	9.2	7.8

Rumination

To assess rumination, participants rated their four biggest worries on a 3 point scale (1=sometimes, 2=often, 3=always). Scores were totalled, to yield a rumination score out of a possible 12. Rumination scores ranged from 2 to 12 in the ASD group, with a median of 9 (interquartile range = 6). For the control group, rumination scores ranged from 2 to 12, with a median of 7 (interquartile range = 5). No significant difference was found between the two groups' rumination levels, highlighted by a Mann-Whitney test ($U=212$, $z=-.710$, $p>0.05$). A small effect size was found ($r=0.11$).

Distress

Participants rated their four biggest worries on another 3 point scale (1=a little, 2=quite, 3=a lot), to gauge distress. Scores were totalled, to give a distress score out of a possible 12. In the ASD group, distress scores ranged from 3 to 12, with a median of 10 (interquartile range = 5). Distress scores in the control group ranged from 1 to 11, with a median of 7 (interquartile range = 5). A Mann-Whitney test showed that there was a significant difference between the two groups' levels of distress (U=145, z=-2.291, $p<0.05$). A medium effect size was found (r=0.35).

Anxiety

Each participant completed the GAS-ID. For the ASD group, the mean score was 26.1 (SD=9.2). The mean score was 17.9 (SD=7.8) for the control group. An independent t-test found this difference to be significant: t (42) =3.197; $p<0.05$. There was a medium to large effect size (r=0.44).

Within Group Associations

The Spearman Correlation Coefficient was used to measure within group associations between rumination, distress, and anxiety for the ASD group; whilst the Pearson Correlation Coefficient analysed within group associations between rumination, distress, and anxiety for the control group.

Rumination and Distress

For the ASD group, a highly significant positive association between rumination and distress was found: rs=.84, $p<0.01$, highlighting a large effect size. Likewise, a highly significant positive association between rumination and distress was found for the control group: rp=.85, $p<0.01$, indicating a large effect size.

Rumination and Anxiety

For the ASD group, a significant positive association between rumination and anxiety was found: rs=.67, $p<0.05$, highlighting a large effect size. A highly significant positive association between rumination and anxiety was found for the control group: rp=.79, $p<0.01$, again showing a large effect size.

Distress and Anxiety

A significant positive association between distress and anxiety was found for the ASD group: $rs:=.59$, $p<0.05$, showing a large effect size. For the control group, a highly significant positive association between distress and anxiety was found: $rp=.83$, $p<0.01$, indicating a large effect size.

Discussion

Notable differences were found in the content and salience of worries experienced by adolescents with and without ASD. There was no significant difference found in rumination between the two groups. However, the ASD group were significantly more distressed about their worries, and also had significantly higher levels of anxiety. Finally, significant positive correlations between rumination, distress, and anxiety were found for both participant groups**.**

Failure was a salient worry for both groups, specifically related to exams, perhaps reflecting the approach to the exam period. Likewise, work, specifically finding a job, was a major concern for the non-ASD group as they contemplated leaving school. Worry content for typically developing adolescents can be compared to the study by Young et al. (2016), as both studies employed a control group of typically developing young people aged 16-18. The findings correspond with one another, as the control group's most common worry content for the topics of work, further education, money, failure, and school in the Young et al., (2016) study matched the control group's in the present project (Young et al., 2016).

The current study found differences in worry content and salience between the two groups. For instance, regarding socially-orientated topics, participants with autism were concerned about being excluded, as well as about interactions in a range of settings including work and school. In contrast, individuals without ASD did not commonly express worries about socialising, instead concerns themed around losing contact with people. In addition, concerns surrounding unexpected changes and coping with noise were prominent for participants with ASD, whilst sensory worries were not commonly reported by the control participants. Although it should be noted that sensory concerns were not amongst the ASD group's most salient worries. Previous focus group research has found that children with ASD were worried about sensory triggers, socialising, and changes to routine (Ozsivadjian et al., 2012). Another interview study involving adolescents with ASD found themes relating to school challenges, unpredictability, and social concerns (Cage et al., 2016). Prominent worries specific to adolescents with ASD found in the current study, including socialising, unexpected change, and coping with noise are comparable to the limited existing worry literature.

Research investigating interaction experiences in adolescents with high-functioning autism have found that they often feel like they don't fit in (Portway & Johnson, 2003), and have desires to make friends but believe they lack the abilities (Bauminger et al., 2003). Some have reported to disguise their difficulties by acting like they know how social situations work (Carrington et al., 2003). Adolescents with ASD rarely feel accepted by their peers because of their differences (Humphrey & Lewis, 2008), and can stereotypically be viewed as unsocial and emotionless (Harnum et al., 2007); attitudes which may fuel exclusion. Current findings have shown that individuals with autism are concerned about socialising and being included, adding significance to the notion that although social experiences may be different, there isn't a lack of interest in seeking social contact.

Between-group analyses found that individuals with autism had significantly higher levels of distress and anxiety compared to those without. Our results are consistent with research showing anxiety to be much higher in young people with ASD compared to typically developing and clinically referred peers (van Steensel & Heeman, 2017), and findings which show that the vast majority of adolescents with ASD suffer from anxiety symptoms (White et al., 2009). Caution must be exercised during interpretation of the present study, as anxiety may have been heightened due to approaching exams. Despite this, worrying about mental health was a common worry for participants with ASD; not present in controls. In addition, teachers generally describe anxiety-related difficulties as among the most common presenting problems for young people with ASD (Waddington and Reed, 2006), consistent with our findings. Conversely, there were no significant differences found in rumination scores between the ASD and control group in the current investigation. However, our study had smaller samples than required to detect a significant difference in rumination scores, therefore further research is required to investigate the nature of potential rumination differences.

There are a number of competing explanations about why young people with autism are more likely to develop anxiety. One proposal is that difficulties in social skills and psychological hyperarousal lead to social anxiety (Bellini, 2006). This is consistent with findings regarding social concerns in the present study. Another suggestion proposes that ASD characteristics (such as repetitive behaviours) and anxiety exacerbate each other (Wood & Gadow, 2010). Also, it has been theorised that a neurobiological predisposition to ASD-specific difficulties coupled with environmental factors can contribute to anxiety (van Steensel et al., 2014). ASD-specific concerns reported in the current study (such as worrying about unexpected changes and unfamiliar environments) may have increased anxiety; potentially validating the proposed theories. Furthermore, sensory over-sensitivity in ASD has been linked with higher anxiety (Green and Ben-Sasson, 2010). Reported sensory concerns coupled with high anxiety levels found in the current study support this assertion. However, it should be noted that adolescents with ASD were also found to worry about similar subjects to typically developing adolescents such as money and failing exams, which may also influence anxiety.

Within group analyses found rumination, distress, and anxiety to be significantly associated with each other, bolstering evidence that these worry components are interrelated (Borkovec et al., 1998; Morrison and O'Connor, 2005; Cook et al., 2015). Further theoretical value is added considering our study mirrors outcomes by Forte et al. (2011) which found significant correlations between distress, rumination, and anxiety (Forte et al., 2011). In addition, research has found rumination to be associated with anxiety in people with high-functioning autism (Hare et al., 2015*)*. Current findings may validate the theory that effective problem-solving leads to less rumination and anxiety (Szabo & Lovibond, 2004). In the investigation by Young et al. (2016), a significant association between anxiety and rumination was found in adolescents without IDs, but not in those with IDs (Young et al., 2016). It is possible that limited or uneven problem-solving skills in adolescents with IDs accounted for the non-association. Conversely, significant associations between rumination and anxiety in participants without IDs may be explained by superior problem-solving abilities.

Limitations

Although the researcher spent time building a rapport with participants, the setting may have been perceived as overly formal, which may have generated less detailed responses. Likewise, despite careful selection of appropriate worry topics based on the literature, as well as providing the opportunity for adolescents to discuss additional topics, there is a possibility that some concerns were not discussed. These could potentially include sensitive topics that participants may not have been willing to discuss in an academic study. Correspondingly, there have been known challenges in eliciting the viewpoints of those with ASD. Previous research has shown that young people with ASD have difficulties in expressing emotions and initiating conversations (Preece and Jordan, 2010), and may also display rigid thinking, reducing the ability to answer future or abstract questions (Beresford et al., 2004).

In relation to the measures, it is possible that a participant could worry constantly about a single topic, yet score lower on the rumination scale than a participant who worries less but about a wider range of topics. Likewise, one could also score lower on the distress scale if they were very upset by a single worry, compared with someone only mildly upset by multiple worries. This possible methodological confound is acknowledged. Furthermore, the GAS-ID was used to gauge anxiety in the current study, despite being designed for those with an intellectual disability (Mindham & Espie, 2003). It was chosen because of its potential accessibility to those with high-functioning ASD; a group who may find it difficult to understand emotionally-charged questions posed in conventional anxiety questionnaires. In addition, the measure has been used with non-ID participants in previous studies (Forte et al., 2011; Young et al., 2016). However, the questionnaire has not been validated in people without a learning disability, nor in individuals with ASD. Consequently, the validity of the GAS-ID in the populations of interest is unknown, therefore findings should be interpreted with caution.

The research was conducted during a single time frame when participants were leaving school, thus worries expressed can only apply to this period. Likewise, in relation to timing, the vast majority of participants took part on the lead up to important exams. This may have created a bias towards certain worries such as failing exams, or an increase in anxiety levels; which may have been different if the research were conducted post-exams. Our study did not explore the effects of age or gender on worry, nor did it take into account individual background factors affecting mental wellbeing such as early childhood experiences. Diligent attempts were made to recruit as many participants as possible. However, the researcher was unable to recruit 30 participants in each group, meaning the study was not suitably powered to uncover a difference in rumination scores between both groups. Finally, multiple correlations were run, increasing the risk of type 1 error. Given the study is exploratory, the risk of type 1 error is accepted and findings are acknowledged in light of this limitation.

Further Research

Future longitudinal research into worry across development would help uncover anxieties and challenges at different life stages. The literature suggests that ASD characteristics can be expressed differently in males and females (Krieser & White, 2014), thus exploring gender differences in worry would be an intriguing future direction. Also, it has been proposed that worry is adaptive (Wells, 1995), and that it can serve useful purposes such as preparation for action, decision making and motivation (Floyd et al., 2005). Accordingly, examining the relationship between worry and resilience in young people with and without ASD would be useful to explore. Furthermore, anxiety levels were very high for participants with ASD in the current study. It is estimated that 40% of children with autism meet the diagnostic criteria for an anxiety disorder (van Steensel et al., 2011). It is possible that high anxiety levels indicated participants were vulnerable to developing mental health conditions. Future investigations should consider this potential link.

Implications

The findings from the study have made a valuable contribution to the limited literature regarding views of adolescents with autism, and have added substance to theories regarding anxiety and autism. The study has importantly highlighted common concerns of adolescents with and without autism. This could have benefit in terms of transition planning. Professionals and students collaboratively exploring specific concerns via open discussions could help problem-solve, and reduce anxiety and distress; easing the process during a time of change. This is particularly important considering the difficulties individuals with ASD face during transition including a reduced chance of attending further education (Newman et al., 2011), low employment rates (National Autistic Society, 2016), and high isolation post-school (Howlin et al., 2013).

As well as aiding transition, particular worries that emerged could be applied by services involved in efforts to decrease worry and build resilience. For instance, a didactic programme outlining common concerns of school leavers could be made available to inform understanding and help prevent distress. In addition, school staff and clinicians could use the knowledge of young people's concerns to help identify suitable support. The research has shown increased anxiety in an ASD population, thus it would be worthwhile for professionals to monitor distress in young people and consider anxiety management interventions, in school curriculums and in mental health services.

The Worry Interview tool has been successfully used with young adults and adolescents with and without ID in previous studies (Forte et al., 2011; Young et al., 2016). The tool was adapted in the present study for applicability to adolescents with ASD, and effectively facilitated relevant discussions around worries. The Worry Interview therefore has clinical utility as it can be applied to explore concerns adolescents may find hard to articulate. This is particularly useful for those with ASD where social and communication difficulties are a common barrier. The Worry Interview has proven it can actively engage individuals with ASD in qualitative research. The materials could be further used, developed and refined in future to help elicit detailed viewpoints of young people with autism.

Conclusions

The study is the first to investigate differences in worries between young people with and without ASD as they leave school, adding value to the field. Both groups’ anxiety, rumination, and distress levels correlated with each other; and both groups had a salient fear of failing exams during the approach to the assessment period. Individuals with ASD displayed higher rates of distress and anxiety than their typically developing peers as they approached transition. Adolescents with autism were notably more worried about social challenges, unexpected changes, and sensory issues; highlighting the specific difficult experiences they tend to face.

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Appendix 1 – Systematic Review

Appendix 1.1: Quality Rating Criteria based on Walsh and Downe (2006)

The conventional application of the tool involves rating each item as either: the study fully met the criteria, the study partially met the criteria, or the study did not meet the criteria. In the current review the scoring method was adapted: if a criterion was met, it was marked as present, whilst if the criterion was not indicated, it was marked as absent.

Stage	Essential criteria	Specific Prompts
Scope and purpose	1. Clear statement of focus for research 2. Rationale for research 3. Questions/aims/purpose are stated 4. Study thoroughly contextualised by existing literature	• Clarity of focus demonstrated • Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing • Link between research and existing knowledge demonstrated • Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both
Design	5. Method/design apparent 6. Above consistent with research intent 7. Rationale given 8. Data collection strategy apparent 9. Data collection strategy appropriate	• Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting Appropriate • Were data collection methods appropriate for type of data required and for specific qualitative method? • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?

		• Was triangulation of data sources used if appropriate?
Sampling strategy	10. Sample and sampling method explained 11. Above justified 12. Above appropriate	• Selection criteria detailed, and description of how sampling was undertaken • Justification for sampling strategy given • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained
Analysis	13. Analytic approach explained 14. Above appropriate 15. More than one researcher involved if appropriate 16. Participant involvement in analysis	• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) • Was it appropriate for the qualitative method chosen? • Was data managed by software package or by hand and why? • Discussion of how coding systems/conceptual frameworks evolved • How was context of data retained during analysis • Evidence that the subjective meanings of participants were portrayed • Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance • Did research participants have any involvement in analysis (e.g. member checking) • Evidence provided that data reached saturation or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion/rationale if it was not
Interpretation	17. Context described	• Description of social/physical and

	18. Context taken account of in interpretation 19. Clear audit trail (sufficient so others can follow decision trail) 20. Data used to support interpretation	interpersonal contexts of data collection • Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena • Sufficient discussion of research processes such that others can follow 'decision trail' • Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation led to conclusions
Reflexivity	21. Researcher reflexivity demonstrated	• Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher's influence on stages of research process • Evidence of self-awareness/insight • Documentation of effects of the research on researcher • Evidence of how problems/complications met were dealt with
Ethical dimensions	22. Ethical approval granted 23. Documentation of how consent was managed 24. Documentation of how confidentiality and anonymity were managed	• Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • Evidence of fair dealing with all research participants • Recording of dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed
Relevance	25. There is an account of the study	• Sufficient evidence for typicality specificity

	relevance 26. Links to theories and literature 27. Limitations/weaknesses outlines 28. Outlines further directions for research	to be assessed • Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies • Discussion of how explanatory propositions/emergent theory may fit other contexts • Limitations/weaknesses of study clearly outlined • Clearly resonates with other knowledge and experience • Results/conclusions obviously supported by evidence • Interpretation plausible and ‘makes sense’ • Provides new insights and increases understanding • Significance for current policy and practice outlined • Assessment of value/empowerment for participants • Outlines further directions for investigation • Comment on whether aims/purposes of research were achieved

Appendix 1.2: Second-Order Constructs for Each Study Grouped by Third-Order Constructs

Constructs/ Study	Lacking Social Skills is a Barrier to Progress	Feeling Undervalued	Misunderstandings and the Need for Clear Communication	The Desire for Informed Support and Training	Sensory Overstimulation Increases Work Stress
Muller et al. (2003)	- Job opportunities limited by interviewing poorly - Difficulty reading facial expressions and understanding tone of voice - Awareness that vocational success depended on ability to “fit in.” - Social deficits often kept participants from succeeding even when they were fulfilling their job descriptions in all other respects.	- Lengthy periods of unemployment and/or underemployment, as well as lack of opportunities for career advancement - Frustration at being placed in entry-level positions for which participants were over-qualified. - Isolated instances of vocational success attributed to participants having fortuitously found good job matches or tolerant supervisors. - Hesitant to disclose diagnosis information	- Difficulty uncovering the meanings of a message - Failure to understand instructions, therefore unable to complete work. - Repeated miscommunications often led to poor work evaluations or firings - Supervisors and co-workers need to be explicit to prevent miscommunication - Preference for direct, even blunt, communication. - Supervisors avoid giving vague or partial instructions - Supervisors and co-workers should not just explain how to do things, but should also show	- Recommended support includes assistance with the job search process, on-site job-coaching, facilitation of social interactions, and mentoring services. - Recommendation for autism awareness training - Disappointment with existing levels of knowledge about ASDs among members of the public, employers and co-workers.	Characteristics of a good job match include those that do not result in excessive sensory stimulation
Hurlbutt & Chalmers (2004)	- Difficulty with the social aspect and understanding how to interact - Difficulty getting along with co-workers and employers - Not understanding the social rules of the	- Frequent Unemployment and Underemployment; Not been able to obtain jobs in fields been trained in - Loss of innumerable jobs in the past and frustration at not being able to maintain - Employers need to	- Not understanding what bosses meant	- Support from job coaches/mentors would be most helpful in making employment satisfying. - Participants had strong feelings about employers and co-	- Sensory issues affect employability - People with Asperger Syndrome get sensory overload easily and without being sensitive to this, employers can contribute to the

	environment, not knowing which topics are appropriate to talk about and which are not, having difficulty asking for help.	consider advantages of employing an individual with AS/HFA as they have some qualities that make them a better employee than many NT people.		workers being educated about Autism	person’s stress and anxiety
Griffith et al. (2011)	- Struggles with social interaction makes obtaining and/or retaining a job difficult - Informal socialising in the workplace was a core problem. - Career potential had not been realized because of difficulties with social interaction - Social skills during interviews hinder ASD participants	- Frequent job loss, and being made redundant could have profound effects on participants’ sense of self-worth. - Numerous, often short-term jobs over the years - Negative work experiences impact on participants’ sense of self-worth	- Receiving unclear instructions has become an ongoing obstacle, thus cannot properly complete work.	- Paucity of knowledge about Asperger syndrome among employers and work colleagues - Participants found support agencies to be ineffective, as they know nothing or very little about Asperger syndrome.	/
Krieger et al. (2012)	- To feel socially accepted and tolerated was essential for the work environment.	- Meaningful occupations are a motivating factor for participants to do work. - Practicalities and consequences of disclosure varied among participants	- Workplaces with clear structures and explicitly communicated hierarchies were preferred.	/	- Sensory perception stress: loud surroundings, crowds of people, and being touched unexpectedly were negative.
Baldwin & Costley (2016)	- Social aspects of work are a significant challenge	- Abilities would often go unrecognised or be devalued in the workplace - Securing part-time work was not always a straightforward	- Simple communication tasks could feel overwhelming. - Difficulties in comprehending tasks and following instructions	- Many needed the help and support of others if they were to achieve their creative pursuits	- Challenges experienced with cognitive ‘overload’

McKnight-Lizotte (2018)	- Eye contact was a job interview barrier - Struggles to understand the social rules and norms involving social interactions with co-workers	/	- Positive supervisory interactions include enforcing the rules without micro-managing - Negative supervisory interactions include lack of communication - Necessity of detailed employer instructions regarding work tasks and expectations - Instructions in writing or modelling tasks are effective - Lack of feedback can impact job performance - Intercommunication with customers is a difficulty - Advantageous communication coping strategies such as role-play	- Communication interventions or social strategies assisted social skill development - Job training videos were helpful for improving social skills - Chat programme utilises interactions between co-workers	/
Sosnowy et al. (2018)	- Efforts to find work hindered by difficulties with social communication, particularly job interviews.	- Self-employment would overcome challenges in getting or keeping a job. - Focus on specific skills and flexibility to work on own. - Some young adults were reluctant to disclose their autism diagnosis	- Verbal speech challenges difficult for employers to accommodate	- Providing training for employers to help support employees on the autism spectrum - Guidance in searching for a job and navigating the workplace would be beneficial – CV writing, interviewing, social interactions. - Need help to secure employment and accommodations to keep job	- Successful work experiences were places that fit the young adult’s preferences such as quiet environment

Appendix 1.3: Improving reporting of meta-ethnography: the eMERGe reporting guidance based on France, Cunningham et al., (2019)

If a criterion was met, it was marked as present with an 'X', whilst if a criterion was not met, it was marked as absent with a '/'.

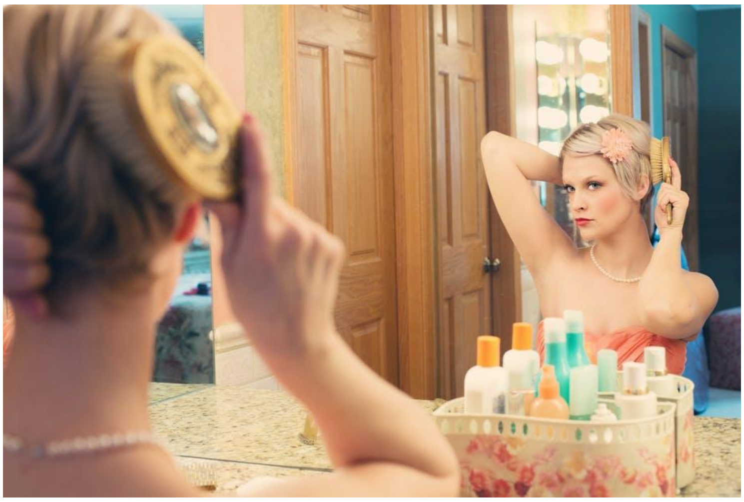
Criteria Headings	Reporting Criteria	Criteria Met
Phase 1: Selecting meta-ethnography and getting started		
1. Rationale and context for the meta-ethnography	Describe the gap in research or knowledge to be filled by the meta-ethnography, and the wider context of the meta-ethnography	X
2. Aims of the meta-ethnography	Describe the meta-ethnography aim(s)	X
3. Focus of the meta-ethnography	Describe the meta-ethnography review question(s) (or objectives)	X
4. Rationale for using meta-ethnography	Explain why meta-ethnography was considered the most appropriate qualitative synthesis methodology	X
Phase 2: Deciding what is relevant		
5. Search strategy	Describe the rationale for the literature search strategy	X
6. Search processes	Describe how the literature searching was carried out and by whom	X
7. Selecting primary studies	Describe the process of study screening and selection, and who was involved	X
8. Outcome of study selection	Describe the results of study searches and screening	X
Phase 3: Reading included studies		
9. Reading and data extraction approach	Describe the reading and data extraction method and processes	X
10. Presenting characteristics of included studies	Describe characteristics of the included studies	X
Phase 4: Determining how studies are related		
11. Process for	Describe the methods and processes for determining how the included	/

determining how studies are related	studies are related: - Which aspects of studies were compared AND - How the studies were compared	
12. Outcome of relating studies	Describe how studies relate to each other	X
Phase 5: Translating studies into one another		
13. Process of translating studies	Describe the methods of translation: - Describe steps taken to preserve the context and meaning of the relationships between concepts within and across studies- Describe how the reciprocal and refutational translations were conducted- Describe how potential alternative interpretations or explanations were considered in the translations	/
14. Outcome of translation	Describe the interpretive findings of the translation	X
Phase 6: Synthesising Translations		
15. Synthesis process	Describe the methods used to develop overarching concepts (“synthesised translations”). Describe how potential alternative interpretations or explanations were considered in the synthesis	X
16. Outcome of synthesis process	Describe the new theory, conceptual framework, model, configuration, or interpretation of data developed from the synthesis	X
Phase 7: Expressing the Synthesis		
17. Summary of findings	Summarize the main interpretive findings of the translation and synthesis and compare them to existing literature	X
18. Strengths, limitations and reflexivity	Reflect on and describe the strengths and limitations of the synthesis: - Methodological aspects—for example, describe how the synthesis findings were influenced by the nature of the included studies and how the meta-ethnography was conducted.- Reflexivity—for example, the impact of the research team on the synthesis findings	/
19. Recommendations and Conclusions	Describe the implications of the synthesis	X

Appendix 2 – Major Research Project

Appendix 2.1: Examples of Pictures Conveying Worry Topics in the Worry Interview

Appearance:



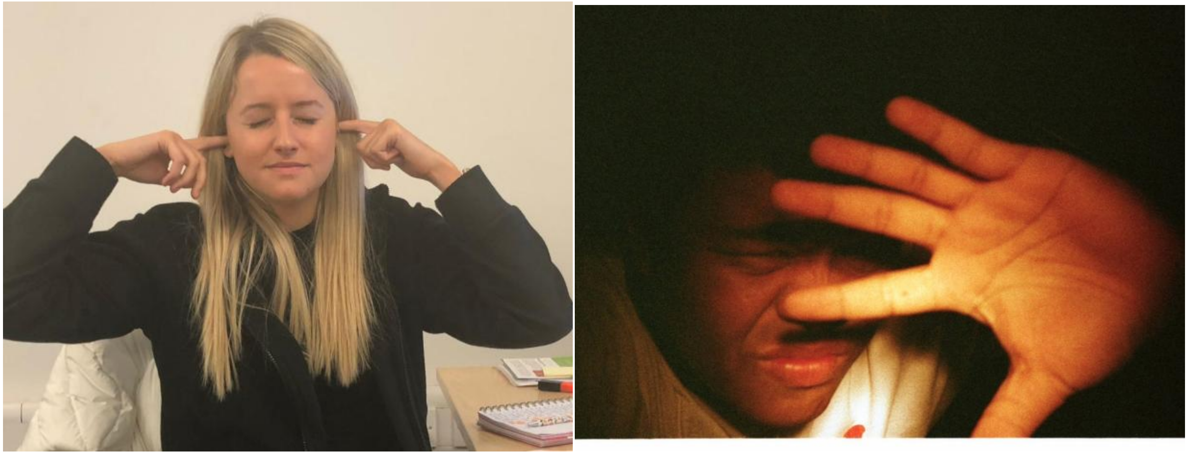
Change:

Failure:

Friendship:

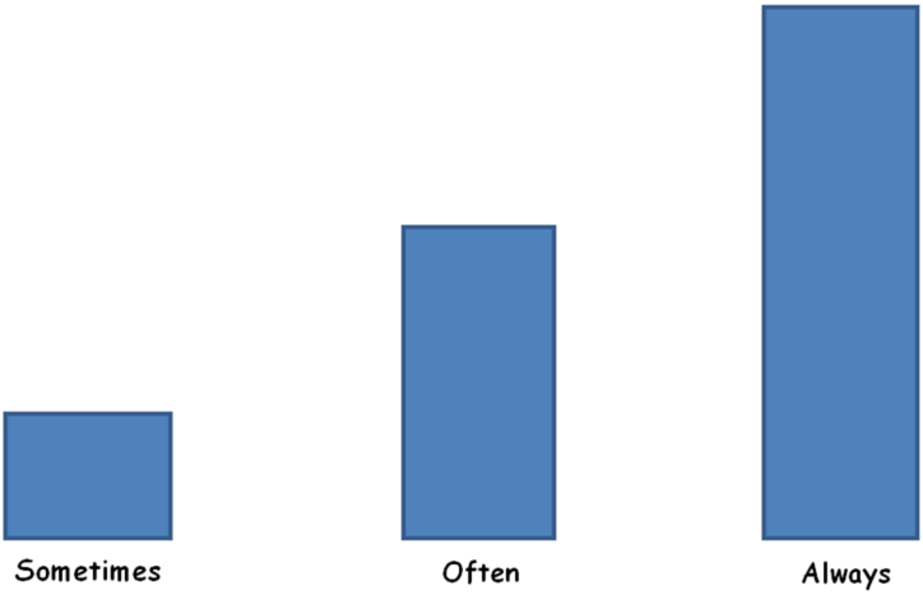
Loneliness:

Sensory:



Appendix 2.2: Rumination and Distress Scales

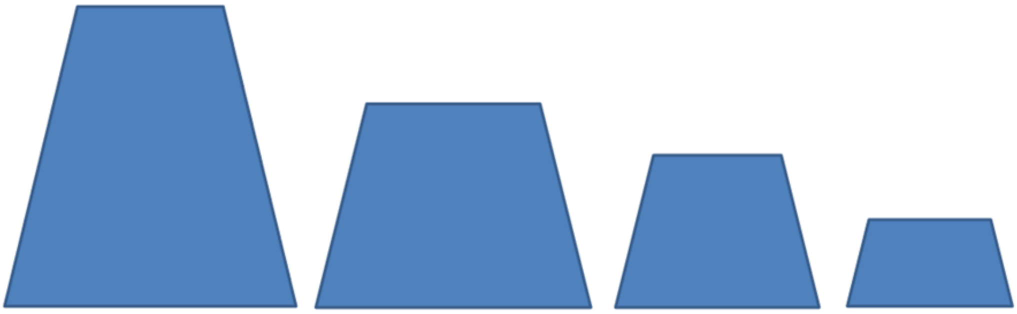
How often do you worry about this?



How upset do you feel when you think about this?

Appendix 2.3: 'Four Biggest Worries' Visual Aid

Rate your four biggest worries (from biggest to smallest)



Appendix 2.4: GAS-ID

Items are scored either 0 - 'never felt like this', 1 - 'sometimes felt like this' or 2- 'always felt like this/ felt like this a lot'.

1) Do you worry a lot? *(... feel worked up/ wound up/ uptight/ up to high doh)*
2) Do you have lots of thoughts that go round in your head? *(...thoughts that you can't stop/ come from nowhere)*
3) Do you worry about your parents/ family?
4) Do you worry about what will happen in the future? *(tailored to the individual eg. ... what will happen if you can't live with your mum anymore)*
5) Do you worry that something awful might happen?
6) Do you worry if you do not feel well? *(... if you feel sick)*
7) Do you worry when you are doing something new? *(... like for the first time)*
8) Do you worry about what you are doing tomorrow?
9) Can you stop worrying? (reverse score)
10) Do you worry about death/ dying?
11) Do you get scared in the dark*? (... think of being in bed with the lights out; would you be scared)*
12) Do you feel scared if you are high up? *(... think of being up a high building ...)*
13) Do you feel scared in lifts or escalators? *(... would you go in)*
14) Are you scared of dogs? *(... would you stroke/ clap)*
15) Are you scared of spiders? *(... would you go near)*
16) Do you feel scared going to see the doctor or dentist?
17) Do you feel scared meeting new people?
18) Do you feel scared in busy places? *(... like crowds, shopping centre)*
19) Do you feel scared in wide open spaces? *(... nothing round about you)*
20) Do you ever feel very hot or sweaty? *(... all hot and bothered)*
21) Does your heart beat faster?
22) Do your hands and legs shake?
23) Does your stomach ever feel funny, like butterflies?
24) Do you ever feel breathless? *(... hard to breathe/ out of breath)*
25) Do you feel like you need to go to the toilet more than usual? *(... for a 'pee')*
26) Is it difficult to sit still? *(... feel you can't sit at peace)*
27) Do you feel panicky? *(... get into a panic/ a 'state')*

Appendix 2.5: Study Consent Form

Study Consent Form

Title: A Comparison of the Content and Nature of Worries of Young People with and without Autism Spectrum Disorder as they Transition out of School.

Researchers: Jack Waldman (Trainee Clinical Psychologist), Professor Andrew Jahoda (Consultant Clinical Psychologist) & Dr Ann McPaul (Clinical Psychologist)

Please sign your initials in the boxes if you agree

I confirm that I have read and I understand the participant information sheet for the above study and that I have been given the opportunity to ask any questions relating to the study. ☐

I understand that I am under no obligation to participate in this study. It is entirely voluntary and I can withdraw at any time, without giving reason. ☐

I am aware that the interview will be recorded by the researcher, Jack Waldman, and only used for the purpose of the research study, as described in the participant information sheet. ☐

I am aware and understand that my researcher, Jack Waldman, may publish direct quotations said by me during the interview in the anonymised format. ☐

I understand that all names, places and anything that could identify me will be removed and nothing that identifies me will appear for others to see. All collected data will be stored for up to 10 years at the University of Glasgow in accordance with relevant laws. ☐

I am aware that the researcher may be required to tell an appointed support person, if I mention something during the session that makes the researcher concerned about my safety or the safety of others. ☐

I agree to take part in the above study ☐

Printed Name of Participant:

Signature of Participant: Date:

Printed Name of Researcher:

Signature of Researcher: Date:

Consent Form Version Two, dated 05/10/2018 (1 copy for participant; 1 copy for researcher)

Appendix 2.6: Study Information Sheet

University of Glasgow | College of Medical, Veterinary & Life Sciences

Study Information Sheet

Title: A Comparison of the Content and Nature of Worries of Young People with and without Autism Spectrum Disorder as they Transition out of School

You are being invited to take part in a research study. The research study is voluntary so you do not have to take part. Before you decide if you want to take part, it is important for you to know why the research is being done and what it will involve. This information sheet will tell you about these things.

Who I am

My name is Jack Waldman and I am a Trainee Clinical Psychologist. I am carrying out this study with help from my supervisors: Professor Andrew Jahoda who is a University Professor and a Consultant Clinical Psychologist, and Dr Ann McPaul who is a Clinical Psychologist.

What is this study about?

This study is happening to help us understand more about the types of things that young people with Autism Spectrum Disorder (ASD), and young people without ASD worry about before they leave school.

Why are we doing this study?

It is important for us to know what types of things young people with and without ASD worry about. Knowing about these things will help the schools know how they can help people to feel more confident. The study will run for 10 months.

Why have I asked you to do this study?

You have been asked because you go to school in the Highland area and you are aged either 16 or older. I am trying to meet with 60 young people aged 16-18 who go to school in the Highlands to find out more about these worries.

You do not have to take part in this study.

It is up to you to decide whether or not to take part in this study. It is okay if you decide that you don’t want to take part. You don’t have to tell anyone why you don’t want to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

It’s also okay to start taking part in the project and then change your mind. You still won’t have to give a reason for changing your mind and you will still keep the information sheet and consent form.

What is involved?

I would ask to meet with you once for around 40 minutes at your school. During our meeting I would ask about the types of things that you worry about. I would bring pictures that we can use to help us talk about these worries. There are no right or wrong answers. If 40 minutes feels like too long, then we could meet for two shorter sessions instead. I would record what we say on a voice recorder to help me remember the things that you have told me. I will also ask you to complete a short questionnaire about worry, and two brief reasoning tasks.

Benefits of taking part

We won’t give you a specific reward for taking part in our study. However, we hope that you will like sharing some of things that are on your mind. By taking part in this study, we will be able to know more about the types of things young people worry about before they leave school. This can help other people to know what supports young people should be given before they leave school.

Bad things about taking part

You will miss about 40 minutes of a class to take part in this study. Other than that, there shouldn’t be anything bad that happens if you decide to take part. However, there is a chance that you might find talking about your worries difficult. If you feel upset when talking about your worries, it is important that you tell the researcher. The researcher can chat with you about it first. If you wanted to talk to someone else about your concerns, the researcher would help you get the right support.

What will happen to your information after we meet?

All of the information that you give me in our meeting will be kept safe in a locked drawer and on a password protected computer. This means that no one apart from me and my supervisors will be able to see the information that you shared with me. Information gathered will have a participant code applied to it, meaning any information about you will have your name removed so that you cannot be recognised from it.

However, if you say something during the interview which makes the researcher concerned about your safety or the safety of others, the researcher may be required to tell a support person involved in your care (e.g. GP or parent/guardian). Where possible, the researcher will discuss this with you beforehand and tell you if he is going to do this, whilst explaining why. Support from a named person and parent or guardian will be established pre-appointment to contact in the event of an issue.

All study data will be held in accordance with The General Data Protection Regulation (2018). Project data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures.

What will happen to the results of the study?

Once I have spoken to all the young people who want to be involved in the study, I will write about what I have found out in a paper that may be read by other people. None of the participants will be named in this paper so that no one else knows that I spoke to you. I might use direct quotes of what you have told me, but these won't include your name or any details about your life, so no one will be able to identify you.

I can also give you a copy of the results of the study.

Other questions about the study

If you have any more questions about the study then you can get in touch with me.

You can write to me at: Jack Waldman, Trainee Clinical Psychologist
Adult Mental Health Service, Drumossie Unit, New Craigs Hospital, Inverness, IV3 8NP

Or you can email me at: j.waldman.1@research.gla.ac.uk

Or you can call me at: 01463 XXX XXX

Or you can get in touch with my Academic Supervisor: Professor Andrew Jahoda

Address: Institute of Mental Health and Wellbeing, University of Glasgow, Gartnavel Hospital, Glasgow, G12 0XH

Phone Number: 0141 XXX XXXX

Email: Andrew.jahoda@glasgow.ac.uk

If you are interested in taking part…

If you would like to take part, please complete the tear-off slip on the next page and return it to your class teacher, who will have a box labelled 'Research study tear off slips'. Alternatively, you can post it back to me in the stamped addressed envelope provided.

Thank you for taking the time to think about this study.

Study Title: A Comparison of the Content and Nature of Worries of Young People with and without Autism Spectrum Disorder as they Transition out of School

Your Name:

Your Signature:

Your Telephone Number:

Do you have Autism? (Please Circle) Yes/No

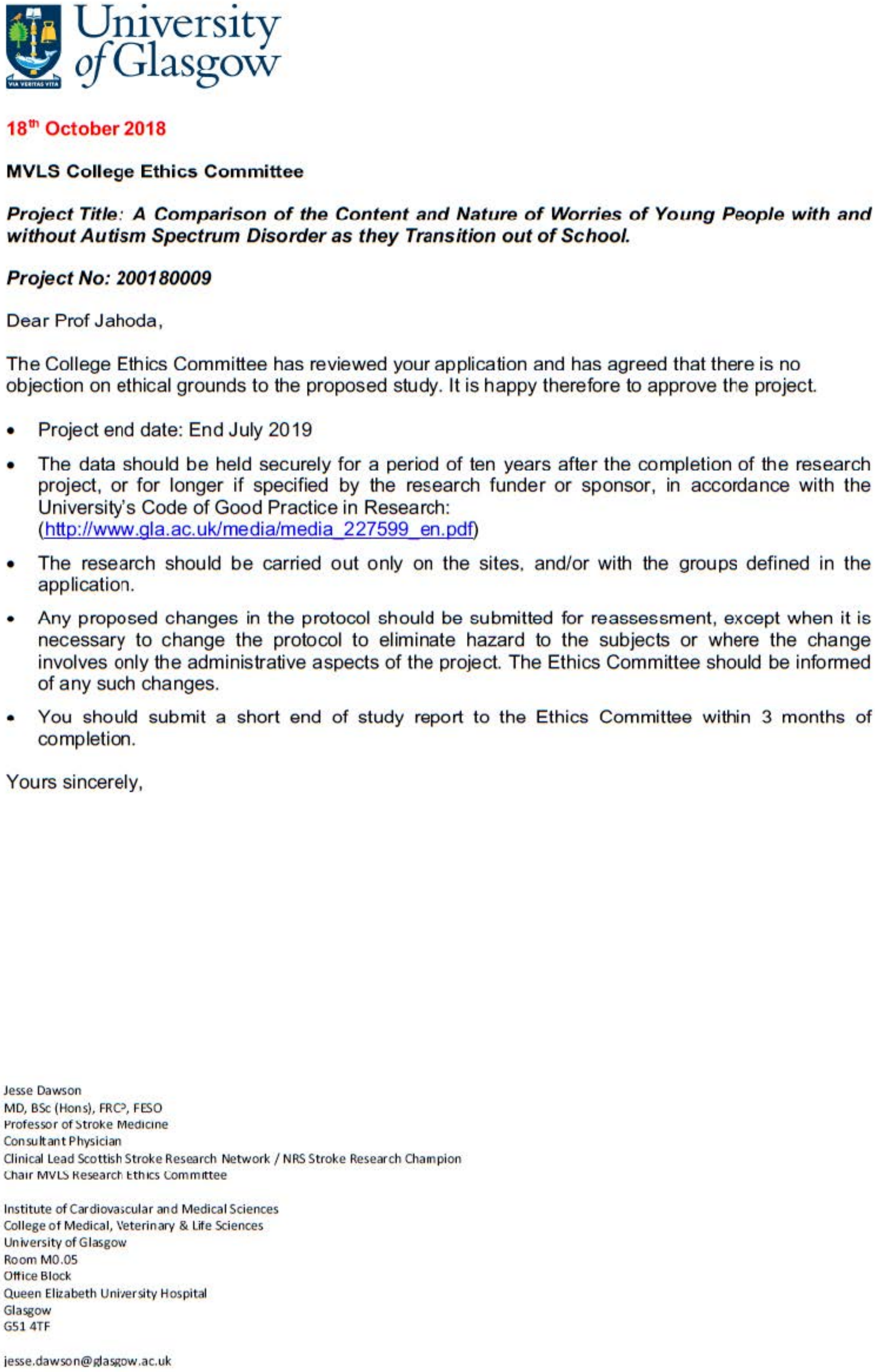
For office use: Please contact Jack Waldman, Trainee Clinical Psychologist.

Contact Number: 01463 253 697 Email: j.waldman.1@research.gla.ac.uk

Address: Adult Mental Health Service, Drumossie Unit, New Craigs Hospital, Inverness, IV3 8NP

Information Sheet Version Two. Dated 05/10/2018.

Appendix 2.7: Copy of the MVLS Ethical Approval Letter



University of Glasgow

18th October 2018

MVLS College Ethics Committee

Project Title:* *A Comparison of the Content and Nature of Worries of Young People with and without Autism Spectrum Disorder as they Transition out of School.

Project No: 200180009

Dear Prof Jahoda,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: End July 2019
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Professor of Stroke Medicine
Consultant Physician
Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion
Chair MVLS Research Ethics Committee

Institute of Cardiovascular and Medical Sciences
College of Medical, Veterinary & Life Sciences
University of Glasgow
Room M0.05
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Glasgow
G51 4TF

jesse.dawson@glasgow.ac.uk

Appendix 2.8: Worry Content in ASD Group

Autism Worry School – 12/22 participants worried about topic (54.5%)	
Categories	**No of Participants Worried about each Category**
Worrying about the exams	5 (22.7%)
Worrying about coursework	5 (22.7%)
Worrying about social interactions in school	4 (18.2%)
Worrying about the noisy environment	2 (9.1%)
Worrying about getting into higher education	1 (4.5%)
Worrying about not having enough energy in school	1 (4.5%)

Autism Worry Further Education – 15/22 participants worried about topic (68.2%)	
Categories	**No of Participants Worried about each Category**
Worrying about being in a different and less familiar environment	6 (27.3%)
Worrying about moving away from home	5 (22.7%)
Worrying about living independently and looking after myself	4 (18.2%)
Worrying about being away from people close to me	3 (13.6%)
Worrying about struggling with the work	3 (13.6%)
Worries about not having enough money	2 (9.1%)
Worrying about socialising at college/university	2 (9.1%)
Worrying about not knowing what I want to do at college/university	2 (9.1%)
Worrying about the attire worn at college/university	1 (4.5%)
Worrying about being accepted in appearance	1 (4.5%)
Worrying about interviews	1 (4.5%)

Autism Worry Family – 5/22 participants worried about topic (22.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about family members' general happiness and wellbeing	3 (13.6%)
Worrying about family members' physical health	2 (9.1%)
Worrying about fights in the family	1 (4.5%)
Worrying about not keeping in touch with family in future	1 (4.5%)
Worrying that family will be overbearing in future	1 (4.5%)

Autism Worry Friendship – 14/22 participants worried about topic (63.6%)	
Categories	**No of Participants Worried about each Category**
Worrying about finding socialising difficult	7 (31.8%)
Worrying about losing friends	6 (27.3%)
Worrying about being unable to make friends	4 (18.2%)
Worrying about being unable to trust friends	3 (13.6%)
Worrying about upsetting or offending friends	2 (9.1%)
Worrying about not being able to keep in touch with friends	2 (9.1%)
Worrying about arguments with friends	2 (9.1%)
Worrying about being judged because of my condition	1 (4.5%)

Autism Worry Relationships – 9/22 participants worried about topic (40.9%)	
Categories	**No of Participants Worried about each Category**
Worries about the social skills required for a relationship	5 (22.7%)
Worries about not having been in a relationship before	3 (13.6%)
Worries about maintaining a relationship	3 (13.6%)
Worries about being alone in future	2 (9.1%)
Worrying about the expectation and pressure to be in a relationship	1 (4.5%)
Worries about low self-confidence when seeking relationships	1 (4.5%)
Worries about the lack of people in my area	1 (4.5%)
Worries about not dating due to sexuality	1 (4.5%)

Autism Worry Bullying - 5/22 participants worried about topic (22.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about attitudes of others towards bullying	3 (13.6%)
Worrying about bullying that I'm experiencing right now	2 (9.1%)
Worrying that I'll be bullied in the future	1 (4.5%)

Autism Worry Loneliness – 10/22 participants worried about topic (45.4%)	
Categories	**No of Participants Worried about each Category**
Worrying about not being included socially	3 (13.6%)
Worrying about not having any friends currently	2 (9.1%)
Worrying about difficulties in speaking to others	2 (9.1%)
Worrying about not having support when needed	2 (9.1%)
Worrying about being lonely for a long time	2 (9.1%)
Worrying about not seeing friends outside of school	1 (4.5%)
Worrying about losing someone in a relationship	1 (4.5%)
Worrying about not making more friends in future	1 (4.5%)
Worrying about losing friends	1 (4.5%)
Worrying about being away from family when I go to university	1 (4.5%)

Autism Worry Work – 16/22 participants worried about topic (72.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about conversing with other people in a work setting	5 (22.7%)
Worrying about ending up with a job that I don't enjoy	2 (9.1%)
Worrying that I don't know what I want to do	2 (9.1%)
Worrying about schoolwork	2 (9.1%)
Worrying about getting into chosen field	2 (9.1%)
Worrying about exams	2 (9.1%)
Worries about being unable to work because of physical health	1 (4.5%)
Worrying about what work will be like	1 (4.5%)
Worrying about being unable to cope with workload	1 (4.5%)
Worrying about disclosing diagnosis to employers	1 (4.5%)
Worrying about pressure and expectations of getting a good career	1 (4.5%)
Worrying that I won't be able to get a job generally	1 (4.5%)

Autism Worry Money – 11/22 participants worried about topic (50%)	
Categories	**No of Participants Worried about each Category**
Worrying about not having enough money in future	6 (27.3%)
Worrying about not having enough money at the moment	5 (22.7%)
Worrying about having enough money for material possessions	2 (9.1%)
Worrying about having to find a job to earn enough money	1 (4.5%)
Worrying about being unable to work to earn money due to physical illness	1 (4.5%)
Worrying about money exploiting others	1 (4.5%)
Worrying about losing money	1 (4.5%)
Worrying about not being able to afford a home	1 (4.5%)
Worrying about not understanding money	1 (4.5%)

Autism Worry Home – 8/22 participants worried about topic (36.4%)	
Categories	**No of Participants Worried about each Category**
Worrying about family arguments	3 (13.6%)
Worries about being unable to afford housing	2 (9.1%)
Worries about moving home	1 (4.5%)
Worries about family (non-specific)	1 (4.5%)
Worries about having to live with parents	1 (4.5%)

Autism Worry Appearance – 5/22 participants worried about topic (22.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about my eating habits	2 (9.1%)
Worrying about not taking care of my appearance in future	1 (4.5%)
Worrying about being bullied by others because of my appearance	1 (4.5%)
Worrying about not looking the way I want to look	1 (4.5%)
Worrying about my weight	1 (4.5%)

Autism Worry Health – 11/22 participants worried about topic (50%)	
Categories	**No of Participants Worried about each Category**
Worrying about own physical health condition	6 (27.3%)
Worrying about my mental health	5 (22.7%)
Worrying about missing out on things because of my health	4 (18.2%)
Worrying about the physical health of those close to me	4 (18.2%)
Worrying about not looking after myself as much as I should	2 (9.1%)
Worrying about the mental health of those close to me	1 (4.5%)
Worrying about not having the social skills to contact doctor	1 (4.5%)
Worrying about inheriting a health condition in future	1 (4.5%)

Autism Worry Decisions – 18/22 participants worried about topic (81.8%)	
Categories	**No of Participants Worried about each Category**
Worrying about making any type of decision (non-specific)	10 (45.5%)
Worrying about the future consequences of my decisions (generally)	10 (45.5%)
Worrying about deciding where to live in future	2 (9.1%)
Worrying about choosing further education course	2 (9.1%)
Worrying about what job I should do	1 (4.5%)
Worrying about making decisions related to money	1 (4.5%)
Worrying about making decisions related to social life	1 (4.5%)
Worrying about doubting myself	1 (4.5%)
Worrying about deciding which subjects to do next year	1 (4.5%)

Autism Worry Failure – 20/22 participants worried about topic (90.9%)	
Categories	**No of Participants Worried about each Category**
Worrying about failing exams	13 (59.1%)
Worrying about letting myself down	4 (18.2%)
Worrying about not doing well in schoolwork	3 (13.6%)
Worrying about the future impact of failing generally	3 (13.6%)
Worrying about failing to get into further education course	3 (13.6%)
Worrying about failure to get a job	3 (13.6%)
Worrying about not getting qualifications	2 (9.1%)
Worrying about letting other people down	2 (9.1%)
Worrying about having your grades compared to others	1 (4.5%)
Worrying that my autism is holding me back	1 (4.5%)

Autism Worry Death – 14/22 participants worried about topic (63.6%)	
Categories	**No of Participants Worried about each Category**
Worrying about the death of people close to me	9 (40.9%)
Worrying about what happens after death	4 (18.2%)
Worrying about my own death	2 (9.1%)
Worrying about the death of a pet	2 (9.1%)
Worrying about previous experiences of loss	2 (9.1%)
Worrying about finances related to death	1 (4.5%)

Autism Worry Change – 16/22 participants worried about topic (72.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about unexpected changes to plans or routine	7 (31.8%)
Worrying about moving away	4 (18.2%)
Worrying about leaving high school	4 (18.2%)
Worrying about not knowing what will happen in the future	3 (13.6%)
Worrying about changes in technology	1 (4.5%)
Worrying about having to change schoolwork	1 (4.5%)
Worrying about meeting new people	1 (4.5%)
Worrying about going to new places	1 (4.5%)
Worrying about the effort that goes into make changes	1 (4.5%)
Worrying about friends moving away	1 (4.5%)
Worrying about changes to music bands I like	1 (4.5%)
Worrying about people changing	1 (4.5%)
Worrying about going into final school year	1 (4.5%)
Worrying about changes to my environment	1 (4.5%)
Worrying about what other people think of my decisions about making a change	1 (4.5%)

Autism Worry Sensory – 10/22 participants worried about topic (45.5%)	
Categories	**No of Participants Worried about each Category**
Worries about not coping well with noise	9 (40.9%)
Worrying about social implications of having sensory sensitivities	4 (18.2%)
Worrying about not coping well with bright lights	3 (13.6%)
Worrying about not coping well with certain textures	3 (13.6%)
Worries about several conversations happening simultaneously	2 (9.1%)
Worrying about getting headaches from sensory overstimulation	2 (9.1%)
Worrying about going deaf	1 (4.5%)
Worrying about vision deteriorating	1 (4.5%)

Appendix 2.9: Worry Content in Control Group

Control Worry School – 7/22 Participants worried about topic (31.8%)	
Categories	**No of Participants Worried about each Category**
Worrying about the exams	3 (13.6%)
Worrying about coursework	3 (13.6%)
Worrying about others' perceptions if you don't do well	2 (9.1%)
Worrying about not seeing friends after leaving school	1 (4.5%)
Worrying about what to do after school	1 (4.5%)
Worrying about school's lack of resources	1 (4.5%)
Worrying about getting into higher education	1 (4.5%)

Control Worry Further Education – 14/22 participants worried about topic (63.6%)	
Categories	**No of Participants Worried about each Category**
Worrying about getting a place at college/university	7 (31.8%)
Worrying about choosing which college/university to go to	2 (9.1%)
Worrying about moving away from home	2 (9.1%)
Worrying about socialising at college/university	2 (9.1%)
Worrying about not knowing what university will be like	2 (9.1%)
Worrying about not knowing what I want to do at college/university	2 (9.1%)
Worries about being away from people close to me	1 (4.5%)
Worries about living independently and looking after self	1 (4.5%)
Worrying about struggling with the work	1 (4.5%)

Control Worry Family – 4/22 participants worried about topic (18.2%)	
Categories	**No of Participants Worried about each Category**
Worrying about not keeping in touch with family	3 (13.6%)
Worrying about family members' physical health	1 (4.5%)

Control Worry Friendship – 1/22 participants worried about topic (4.5%)	
Categories	**No of Participants Worried about each Category**
Worrying about finding socialising difficult	1 (4.5%)
Worrying about not being able to keep in touch with friends	1 (4.5%)
Worrying about making new friends after school	1 (4.5%)

Control Worry Relationships – 5/22 participants worried about topic (22.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about being alone in future	2 (9.1%)
Worrying about past relationships that have ended	2 (9.1%)
Worrying about finding the person who is right for me	1 (4.5%)
Worrying about the expectation and pressure to be in a relationship	1 (4.5%)
Worrying about the social skills required for a relationship	1 (4.5%)
Worrying about not being supported	1 (4.5%)

Control Worry Bullying - 3/22 participants worried about topic (13.6%)	
Categories	**No of Participants Worried about each Category**
Worrying about people close to me being bullied	2 (9.1%)
Worrying about the impact of bullying on victims in general	1 (4.5%)
Worries about attitudes of others towards bullying	1 (4.5%)

Control Worry Loneliness – 5/22 participants worried about topic (22.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about losing friends	2 (9.1%)
Worrying about not having support when needed	1 (4.5%)
Worrying about being lonely when I get to university	1 (4.5%)
Worrying about close friends being lonely	1 (4.5%)

Control Worry Work – 15/22 participants worried about topic (68.2%)	
Categories	**No of Participants Worried about each Category**
Worrying that I won't be able to get a job	6 (27.3%)
Worrying about ending up with a job that I don't enjoy	3 (13.6%)
Worrying about exams	3 (13.6%)
Worrying about getting into college/university	3 (13.6%)
Worrying that I don't know what I want to do	2 (9.1%)
Worrying about coursework	2 (9.1%)
Worrying about conversing with other people in a work setting	2 (9.1%)
Worries about my performance in my job	2 (9.1%)
Worries about gaining relevant work experience	2 (9.1%)
Worrying about losing a job	1 (4.5%)
Worrying about being unable to cope with the workload at college/university	1 (4.5%)

Control Worry Money – 14/22 participants worried about topic (63.6%)	
Categories	**No of Participants Worried about each Category**
Worrying about not having enough money in the future	10 (45.5%)
Having to find a job to earn enough money	3 (13.6%)
Worrying about not being skilled with money	3 (13.6%)
Not having enough money at the moment	2 (9.1%)
Worrying about the pressure to earn money and be successful	1 (4.5%)
Worrying about owing parents money	1 (4.5%)

Control Worry Home – 3/22 participants worried about topic (13.6%)	
Categories	**No of Participants Worried about each Category**
Worrying about moving out	3 (13.6%)

Control Worry Appearance – 5/22 participants worried about topic (22.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about others judging me for the way I look	4 (18.2%)
Worrying about not looking the way I want to look	1 (4.5%)

Control Worry Health – 9/22 participants worried about topic (40.9%)	
Categories	**No of Participants Worried about each Category**
Worrying about my own physical health condition	3 (13.6%)
Worrying about the physical health of those close to me	2 (9.1%)
Worrying how my health will impact others	1 (4.5%)
Worrying about becoming ill unexpectedly in future	1 (4.5%)
Worrying about maintaining fitness	1 (4.5%)
Worrying about long-term effects of alcohol	1 (4.5%)
Worrying about being unable to play sports because of my health	1 (4.5%)
Worrying about the health risks of sport	1 (4.5%)

Control Worry Decisions – 12/22 participants worried about topic (54.5%)	
Categories	**No of Participants Worried about each Category**
Worrying about choosing further education course	8 (36.4%)
Worrying about the future consequences of my decisions (generally)	6 (27.3%)
Worrying about choosing future job	4 (18.2%)
Worrying about making any type of decision (non-specific)	3 (13.6%)
Worrying about choosing school subjects	3 (13.6%)
Worrying about what to do after school (generally)	3 (13.6%)
Worries about deciding where to live in future	2 (9.1%)
Worrying about whether or not to leave school	1 (4.5%)
Worrying about the decision to end a relationship	1 (4.5%)

Control Worry Failure – 16/22 participants worried about topic (72.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about failing exams	11 (50%)
Worrying about failing to get into further education course	5 (22.7%)
Worrying about others judging you if you fail	3 (13.6%)
Worrying about letting myself down	3 (13.6%)
Worrying about failure to get a job	3 (13.6%)
Worrying about the future impact of failing generally	3 (13.6%)
Worrying about letting other people down	1 (4.5%)
Worrying about failing in sport	1 (4.5%)
Worrying about having to repeat a school year	1 (4.5%)
Worrying about not getting qualifications	1 (4.5%)
Worrying that I'll fail at something that I've tried hard at and spent a lot of time on	1 (4.5%)

Control Worry Death – 8/22 participants worried about topic (36.4%)	
Categories	**No of Participants Worried about each Category**
Worrying about the death of people close to me	7 (31.8%)
Worrying about previous experiences of loss	4 (18.2%)
Worrying that death could happen unexpectedly	2 (9.1%)
Worrying about my own death	2 (9.1%)

Control Worry Change – 5/22 participants worried about topic (22.7%)	
Categories	**No of Participants Worried about each Category**
Worrying about moving away	3 (13.6%)
Worrying about leaving high school	2 (9.1%)
Worrying about not knowing what will happen in the future	2 (9.1%)
Worrying about changes to global environment	1 (4.5%)
Worrying about global political changes	1 (4.5%)

Control Worry Sensory – 4/22 participants worried about topic (18.2%)	
Categories	**No of Participants Worried about each Category**
Worries about not coping well with noise	1 (4.5%)
Worrying about vision deteriorating	1 (4.5%)
Worrying about being in busy cities	1 (4.5%)
Worrying about getting headaches from sensory overstimulation	1 (4.5%)
Worrying about being unable to study when other people are talking	1 (4.5%)

Appendix 2.10: Major Research Project Proposal

DOCTORATE IN CLINICAL PSYCHOLOGY

SUBMISSION FRONT PAGE

Name: Jack Waldman

Matriculation Number:

Name of Assessment: MRP Proposal

Title of Project: A Comparison of the Content and Nature of Worries of Young People with and without Autism Spectrum Disorder as they Transition out of School.

Academic Supervisor: Professor Andrew Jahoda

Field Supervisor: Dr Ann McPaul

(If Applicable)

Clinical Supervisor:
(If Applicable)

Submission Date to Supervisor: 28/05/2018

Version Number:

Word Count: 4212 (including all references)

For Office Use Only

Date Received:

Abstract

Background: The proposed project aims to investigate the content and nature of worries of young people with and without Autism Spectrum Disorders (ASD) as they approach the transition of leaving school. Methods: Roughly 30 typically developing adolescents and 30 adolescents with ASD, aged between 16-18, will be recruited from mainstream schools in the Highland area. A semi-structured "Worry Interview" will be administered to all participants to gauge the content of worries. Participants will rank their four biggest worries. Rumination and distress linked with each main worry will be examined. Participants will also complete a questionnaire to measure their anxiety. Group differences between worry content, rumination, distress, and anxiety levels will be explored using between-subjects comparisons. A within-subjects approach will investigate correlations between anxiety, rumination, and distress for each group. Implications: The nature of worries in adolescents with ASD as they transition out of school will be uncovered, informing the underdeveloped research base. It will advance knowledge regarding the impact of worry in terms of rumination, distress, and anxiety; and influences on worry, such as significant life events. Clinically, outcomes could facilitate support needs and aid mental wellbeing of young people with ASD, as they approach transition.

Introduction

Borkovec (1983) describes worry as a relatively uncontrollable series of thoughts and images regarding potential negative outcomes and their significance (Borkovec, 1983). 'Normal' amounts of worry are accepted as adaptive, and something we all engage in to an extent (Wells, 1995). Worries have been linked to problem-solving (Szabo & Lovibond, 2002), and have been associated with preparation for action, decision making and motivation (Floyd et al., 2005). However, chronic worry can be maladaptive, as it plays a major role in maintaining anxiety disorders (Holaway et al., 2006). Furthermore, research has shown there is a link between rumination and psychological distress (Morrison and O'Connor, 2005). The influence of worry suggests it is a significant characteristic of mental wellbeing.

Worry content varies with sociodemographic factors, such as marital status, educational attainment, gender, and age. For instance, a national UK survey found that those aged 55-74 worried less about relationships, housing, and work, compared to those aged 16-24 (Lindesay et al., 2006). Worry content can also differ due to life experiences. Forte et al. (2011) researched participants with and without an intellectual disability (ID) as they transitioned out of college. Through employing a 'worry interview', significant differences in worry content between the two groups were found, which reflected differences in their social circumstances and past experiences. For example, the non-ID group feared their own death, whilst the ID group's fear of death was linked to concern about coping alone if they lost someone close. Additionally, a prominent worry in the ID group concerned being bullied, due to previous victimisation (Forte et al., 2011).

A follow-up study compared worries in non-ID and ID participants as they left school, and again found that worry content differed due to different groups' life experiences (Young et al., 2016). As well as content, the intensity and frequency of worry can influence mental wellbeing. Worry intensity differentiates non-pathological worry from pathological worry (Cartwright-Hatton, 2006). In the Forte et al. (2011) study, anxiety scores correlated with distress and rumination scores (Forte et al., 2011). Researchers are uncertain as to why this link exists. One theory suggests that pathological worriers experience more distress as they are unable to problem-solve their worries (Szabo & Lovibond, 2004). Other research suggests that metacognitive beliefs regarding worry (such as worry is harmful) could be linked with distress (Cook et al., 2015). One investigation analysed thoughts occurring in adults with Asperger's Syndrome whilst they were anxious, and found that self-focus, rumination lasting over 10 minutes, and worries about everyday events were associated with anxiety (Hare et al., 2015).

There is a growing evidence base regarding the role and content of worry amongst young people in the general population, as well as those with intellectual disabilities. However, research into worry in adolescents with Autism Spectrum Disorder (ASD) is underexplored. ASD refers to a set of heterogeneous neurodevelopmental conditions characterised by communication and social interaction impairments, restricted interests, and repetitive behaviours (APA, 2013). ASD is more prevalent in males than females (Halladay et al., 2015). It is estimated that 40% of children with ASDs meet the diagnostic criteria for an anxiety disorder (van Steensel et al., 2011), and up to 84% suffer from impairing, sub-clinical anxiety symptoms (White et al., 2009). Prevalence rates of anxiety disorders in ASD are considerably higher compared to children with learning disabilities (Gillott et al., 2001), and typically developing children (Kerns and Kendall, 2012). Likewise, anxiety levels of youths with Autism are generally much higher than their typically developing and clinically referred peers (van Steensel & Heeman, 2017). Reasons why young people with ASD are more inclined to developing anxiety are speculative. Social skills deficits and psychological hyperarousal leading to social anxiety is one proposed explanation (Bellini, 2006). Another suggestion is that ASD characteristics (such as repetitive behaviours) and anxiety exacerbate each other (Wood & Gadow, 2010). It has also been theorised that youths with autism have a neurobiological predisposition to ASD specific difficulties, which, coupled with environmental factors (such as bullying or parenting), can contribute to anxiety (van Steensel el al, 2014).

In schools, anxiety-related difficulties are among the most common presenting problems for young people with ASD, according to teachers (Waddington and Reed, 2006). Studies have shown that these issues impact on academic achievement and social functioning (Bellini, 2004; Reaven et al., 2009; Sze and Wood, 2007). One investigation found that some teenagers with Autism can be worried about their reputation in school (Cage et al., 2016). However, in autism research, autistic adolescents' viewpoints are often unheard (Pellicano et al., 2014). Given the prevalence and impact of anxiety, it is important to further uncover the content of worry in adolescents with ASD, and explore the link with levels of rumination, distress, and anxiety.

For all young people, the transition out of high school can be a particularly stressful time, when a young person develops a sense of identity (Eccles et al., 1995). Transition signifies a time of increased independence, often involving the pursuit of a career or further education (Arnett, 2000). For adolescents with ASD, the transition period can be particularly challenging. For example, in the UK, only 16% of adults with autism are in full-time paid employment (National Autistic Society, 2016). Furthermore, the likelihood of attending post-secondary education is lower in the ASD population (Newman et al., 2011). Isolation is common, as youths with ASD often have reduced social contact after leaving school (Howlin et al., 2013). Challenges arising alongside role transitions can influence the development of self-concept and self-esteem (King et al., 2005). For young people with ASD, transition planning is important for improving outcomes after leaving school (Wilczynski, Trammell & Clarke, 2013). Self-determination has been shown to increase with transition planning, which is associated with better post-school outcomes and increased community participation (Sands & Wehmeyer, 1996). However, a systematic review of transition planning programs for young people with ASD showed that all were unable to predict effective transition to employment (Westbrook et al., 2015). Given the difficulties faced, further research is needed to understand the emotional impact and nature of worries as young people with ASD approach the end of school, which in turn could potentially inform appropriate interventions and aid mental wellbeing during transition.

Aims & Hypotheses

Aims

The project is an exploratory investigation, intending to establish an understanding of worries that adolescents with ASD have as they approach transition out of school. Through employing an ASD and a non-ASD control group, the study aims to investigate whether there are differences in the content and nature of worries between the two groups.

Research Questions

C. Are there differences between the ASD and non-ASD groups in terms of:

v) The types of worries described
vi) Rumination levels in relation to the worries
vii) Distress caused by the worries
viii) Anxiety levels

D. Are there positive correlations within groups in terms of:

iv) Anxiety and distress levels experienced in relation to worries

v) Rumination and distress levels experienced in relation to worries

vi) Anxiety and rumination levels experienced in relation to worries

Plan of Investigation

Participants

All participants will be in the transition planning phase of school, aged 16-18. The experimental group will consist of around 30 young people with ASD and the control group will consist of about 30 typically developing adolescents. The two groups will be matched as much as possible in terms of age, gender, socio-economic status, and IQ.

Inclusion Criteria

- English speaking
- Able to provide informed consent
- Aged between 16-18.
- In school, approaching transition.
- ASD group participants will have an ASD diagnosis

Exclusion Criteria

- Individuals with an intellectual disability
- Individuals with significant sensory or physical impairment

Recruitment

Participants will be recruited from mainstream schools in the Highland area. The researcher will contact schools, and liaise with head teachers to discuss the research project. Of the schools opting in, teachers will help identify students who meet the project's criteria. The researcher will issue information sheets to eligible participants.

Measures

A background information sheet will be issued to gather information on participant characteristics including gender, age, and location. The Carstairs Index (Carstairs and Morris, 1991) will be used to determine socio-economic status, which ranks postcodes from affluent to deprived.

To investigate the content and salience of participants' worries, as well as distress and rumination linked with worries, a 'Worry Interview' will be administered. The tool was developed by Forte et al. (2011), in their study investigating worries in college students with and without an ID. Young et al. (2016) used an adapted version in their study with younger participants with ID transitioning in school. The semi-structured interview uses graphic representations of 'worry topics' to unearth a dialogue regarding subjects' concerns. A photograph of a worry topic (such as a picture representing money) is displayed. Participants are then asked, "What is this a picture of?", and "What does this picture make you think of?". To eliminate order effects, topics are randomised across groups. Participants discuss each of the images, then are asked to assign them to one of two piles; either 'no, this is not a worry for me just now', or 'yes, this is a worry for me just now'.

To gauge distress and rumination levels for those assigned to yes, participants are prompted to rate on a 3-point Likert scale how upset thinking about the subject makes them feel (a little, quite, very), and how much they currently worry about the subject (sometimes, often, always). Participants are asked to choose their 4 most prominent worries from the yes pile and rank them from 1-4 (biggest to smallest).

A pilot study of the Worry Interview will be conducted with 2 young people with ASD, who will be excluded from the main project. In their investigation, Forte et al. (2011) chose worry topics from a previous study by Miller and Gallagher (1996), examining worry in adolescents. Young et al. (2016) added more topics to the interview in their pilot study, using worries found from previous research investigating worry in younger children by Silverman et al. (1995). The pilot study will help establish whether necessary alterations need to be made from versions used in previous projects, for applicability to an adolescent ASD population.

The Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID), will be used to measure subjects' anxiety levels. This measure was used with non-ID and ID participants in the Forte et al. (2011) study and Young et al. (2016) study. It is a self-report anxiety questionnaire, applicable to those with and without an ID in our target age group. The test takes 5-10 minutes to complete, has good test-retest reliability ($r=0.95$), internal consistency ($a = 0.96$), and is reasonably correlated with the Beck Anxiety Inventory ($\rho=0.75$) (Mindham & Espie, 2003). Despite our study excluding participants with a learning disability, the GAS-ID may be easier to understand for participants with ASD, compared to other measures with more complex emotion-related language. Thus, it should be sensitive in picking up anxiety symptoms in an ASD population.

The two-subtest form of the Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II; Wechsler, 2011) will be used to provide a measure of intellectual functioning, with the purpose of comparing intelligence of the two groups and ensuring all participants have an IQ above 70. The two-subtest version of the WASI includes "Vocabulary" and "Matrix Reasoning" to yield an overall estimate of cognitive ability.

Design

The project will employ a mixed-methods design. A between-subjects approach will be used to qualitatively explore and compare the content and nature of worries in the ASD and control groups, to uncover any differences or similarities. Between-subjects will again be utilised to quantitatively analyse differences of the impact of worry in terms of anxiety, rumination, and distress experienced. A within-subjects approach will be utilised to quantitively investigate correlations between anxiety, rumination, and distress scores for the ASD and non-ASD groups.

Procedure

Sessions are expected to last around 40 minutes, and will be conducted in a private room based in the participant's school. Participants will be encouraged to talk openly when responding to the Worry Interview and self-report measures. The cognitive assessment will be administered at the end, as to avoid the right or wrong answer nature of the test influencing the free responses in the Worry Interview. To enhance engagement, participants will be allowed to take breaks if needed, and there will be the option to separate the session over two days where required.

Analysis

Themes will be extracted from the pilot study to inform topics to be pictorially represented in the main project. Worry Interviews in the main project will be analysed using content analysis (Strauss, 1987), allowing worries discussed to be categorised, and to highlight the most salient concerns.

Independent t-tests will be employed to analyse differences between anxiety, distress, and rumination scores between both groups. Within-group analyses using Pearson's correlation will explore associations between anxiety, distress, and rumination scores for the ASD and non-ASD group. Parametric assumptions and normality will be analysed, to inform whether non-parametric or parametric tests should be used.

Sample Size Justification

The study is exploratory, aiming to understand the nature of worries in those with ASD during the approach to transition. However, the between-subjects quantitative component in our study employs the same methodology and measures which were used to investigate differences in distress and rumination in young people with and without IDs in the study by Forte et al. (2011). Using t-tests, Forte et al. (2011) found a large effect size of 1.38 for the differences between distress scores of young people with and without IDs. A medium to large effect size of 0.65 was found for the differences between rumination scores. Using the smaller of the two effect sizes (0.65), 30 subjects per group would be needed to find a significant difference between rumination scores. 8 participants in each group would be needed to identify a difference between distress scores between the two groups, using the larger effect size (1.38). Both calculations are based on a power of 0.8 at an alpha level of 0.05 (one-tailed). The study will aim to recruit 30 participants in each group.

Settings and equipment

The researcher will make numerous trips to participant schools throughout the data collection phase, aiming to see several adolescents during each visit. Access to test materials and self-report measures will be needed.

Health and Safety

Participant Issues

Interviews will be conducted at school during school hours. Through liaising with teachers, a contact individual and appropriate room for the appointment will be established. The researcher will monitor participant risk and wellbeing throughout, and support from school staff will be sought should any issues arise.

Researcher Issues

The researcher will familiarise himself with school safety procedures such as who to contact should concerns arise, and what action to take in the event of a fire.

Ethical Issues

Ethical approval will be requested through the University of Glasgow College of Medical, Veterinary and Life Sciences (MVLS) Ethics Committee. Approval will be gained from each Highland Education Department and Local Authorities involved. Data collection, storage and analysis will adhere to the principles of the Data Protection Act (1998). Any electronic files will be stored on secure servers in compliance with university guidelines.

The interviews are intended to provide a comfortable space for participants to discuss their worries openly. Engagement will be encouraged, and participants will be listened to, in a nature equivalent to previous research by Forte et al. (2011) and Young et al. (2016). Participants will have the right to withdraw from the study at any point. Should participants become distressed, the researcher will discuss this in the first instance. Information will then be shared with the relevant support individual. If significant distress occurs, the participant's parent or GP will be contacted. Informed written consent will be gathered from all taking part. Participants will be informed about the study rationale, and will be carefully debriefed after the session is completed.

Financial Issues

WASI-II forms will need to be purchased. WASI-II equipment can be borrowed through the training programme.

Timetable

- 21st May 2018: Final MRP Proposal
- July - September 2018: Apply for and Gain Ethical Approval
- October 2018 – February 2019: Recruitment and Data Collection
- March 2019: Analysis
- April - June 2019: Write up
- July 2019: Final Report Submission
- September 2019: Viva

Practical Applications

Given the literature gap regarding the content and nature of worries in adolescents with ASD, the proposed project will begin to develop an understanding in this area. Project outcomes could inform how to best to accommodate the needs of young people, as they approach the crucial developmental stage of transition.

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Appendix 3: Author Guidelines for Submission to the Journal of Autism and Developmental Disorders

Journal of Autism and Developmental Disorders

Instructions for Authors

EDITORIAL PROCEDURE

Double-Blind Peer Review

MANUSCRIPT FORMAT

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins.

APA Style

Text must be double-spaced; APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The blinded manuscript containing no author information (no name, no affiliation, and so forth).
- The Author Note

TYPES OF PAPERS

Articles, Commentaries Brief Reports, Letters to the Editor

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- Commentary: Approximately 20-25 double-spaced pages maximum, with fewer references and tables/figures than a full-length article.
- A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. May not meet the demands of scientific rigor required of a JADD article – can be preliminary findings.
- A Letter to the Editor is 6 or less double spaced pages with shorter references, tables and figures.

  Style sheet for Letter to the Editor:
- A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information
- The blinded manuscript containing no author information (no name, no affiliation, and so forth):-

  - 6 or less double spaced pages with shorter references, tables and figures
  - Line 1: "Letter to the Editor"
  - Line 3: begin title (note: for "Case Reports start with "Case Report: Title")

- Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

REVIEW YOUR MANUSCRIPT FOR THESE ELEMENTS

1. Order of manuscript pages
Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.
Blinded Manuscript without contact information and blinded Abstract, and References
Appendix
Figure Caption Sheet
Figures
Tables
Author Note

MANUSCRIPT SUBMISSION

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink “Submit online” on the right and upload all of your manuscript files following the instructions given on the screen.

Please ensure you provide all relevant editable source files. Failing to submit these source files might cause unnecessary delays in the review and production process.

TITLE PAGE

The title page should include:

- The name(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address, telephone and fax numbers of the corresponding author

ABSTRACT

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

KEYWORDS

Please provide 4 to 6 keywords which can be used for indexing purposes.

TEXT

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.

- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

BODY

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
- Introduction (The introduction has no label.)
- Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
- Results (Center the heading.)
- Discussion (Center the heading.)

HEADINGS

Please use no more than three levels of displayed headings.

Level 1: Centered
Level 2: Centered Italicized
Level 3: Flush left, Italicized

FOOTNOTES

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

AUTHOR NOTE

The first paragraph contains a separate phrase for each author's name and the affiliations of the authors at the time of the study (include region and country).

The second paragraph identifies any changes in the author affiliation subsequent to the time of the study and includes region and country (wording: "authors name is now at affiliation".)

The third paragraph is Acknowledgments. It identifies grants or other financial support and the source, if appropriate. It is also the place to acknowledge colleagues who assisted in the study and to mention any special circumstances such as the presentation of a version of the paper at a meeting, or its preparation from a doctoral dissertation, or the fact that it is based on an earlier study.

The fourth paragraph states, "Correspondence concerning this article should be addressed to…" and includes the full address, telephone number and email address of the corresponding author.

TERMINOLOGY

- Please always use internationally accepted signs and symbols for units (SI units).

SCIENTIFIC STYLE

- Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.
- Please use the standard mathematical notation for formulae, symbols etc.:
  Italic for single letters that denote mathematical constants, variables, and unknown quantities
  Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative)
  Bold for vectors, tensors, and matrices.

REFERENCES

Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).
  Ideally, the names of six authors should be given before et al.(assuming there are six or more), but names will not be deleted if more than six have been provided.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be italicized.

Please note: that italicization cannot be displayed in the below samples due to a website limitation. The bolded passages should be read as italics.

- Journal article

  Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001). Writing labs and the Hollywood connection. **Journal of Film Writing**, 44(3), 213–245.
- Article by DOI

  Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. **Journal of Molecular Medicine**, https://doi.org/10.1007/s001090000086
- Book

  Calfee, R. C., & Valencia, R. R. (1991). **APA guide to preparing manuscripts for journal publication.** Washington, DC: American Psychological Association.
- Book chapter

O’Neil, J. M., & Egan, J. (1992). Men’s and women’s gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), **Gender issues across the life cycle** (pp. 107–123). New York: Springer.

- Online document

  Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice. Resource document. American Psychiatric Association. http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf. Accessed 25 June 2007.

For authors using EndNote, Springer provides an output style that supports the formatting of in-text citations and reference list.

- EndNote style (zip, 3 kB)

TABLES

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

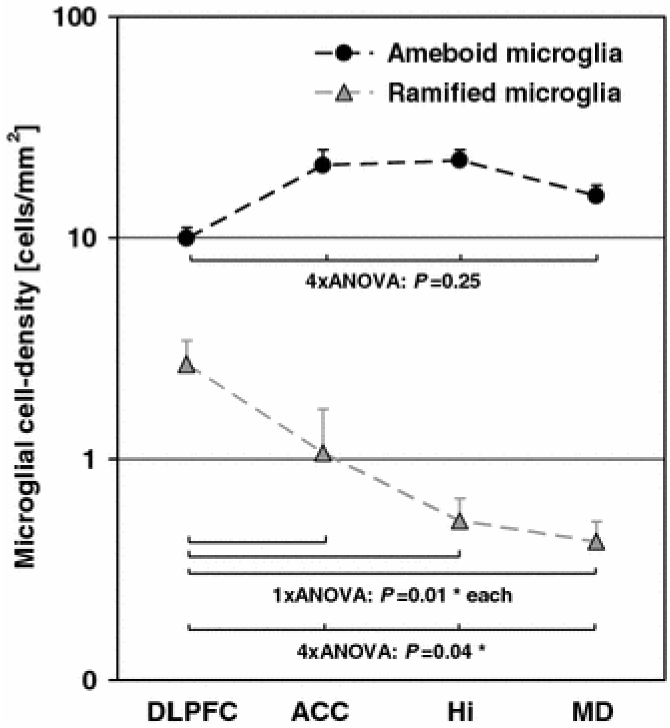
Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

ARTWORK AND ILLUSTRATIONS GUIDELINES

Electronic Figure Submission

- Supply all figures electronically.
- Indicate what graphics program was used to create the artwork.
- For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.
- Vector graphics containing fonts must have the fonts embedded in the files.
- Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

Line Art



- Definition: Black and white graphic with no shading.
- Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.
- All lines should be at least 0.1 mm (0.3 pt) wide.
- Scanned line drawings and line drawings in bitmap format should have a minimum resolution of 1200 dpi.
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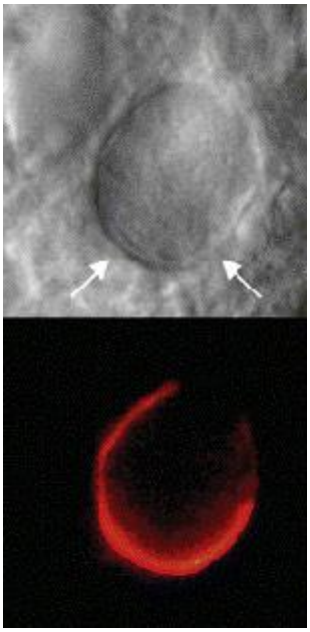
Halftone Art



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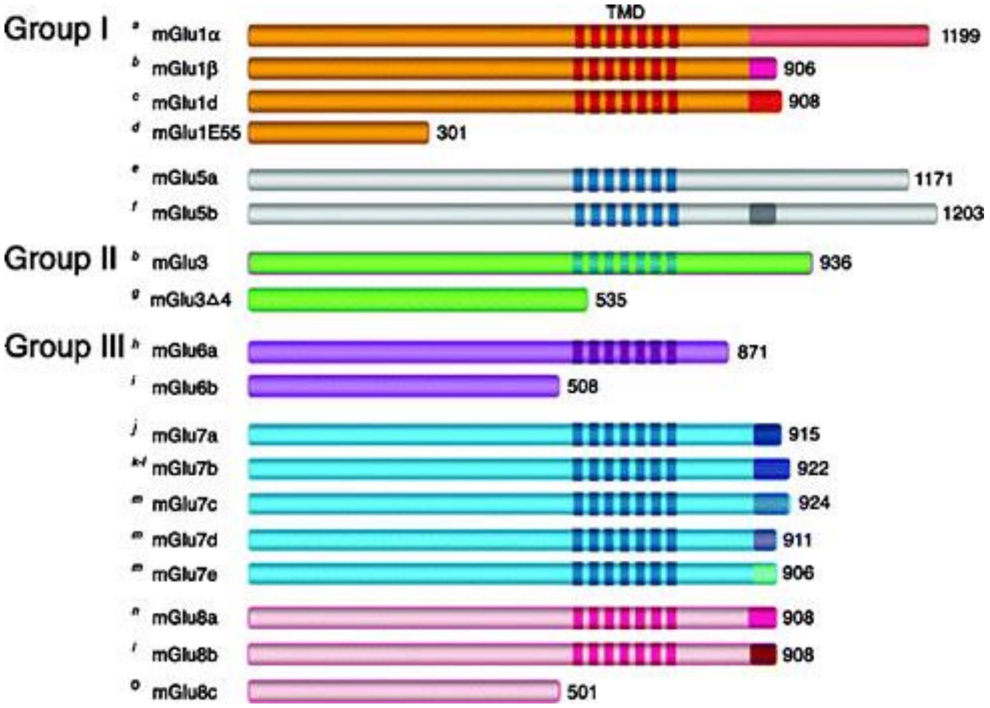

- Definition: a combination of halftone and line art, e.g., halftones containing line drawing, extensive lettering, color diagrams, etc.
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- Color art is free of charge for online publication.
- If black and white will be shown in the print version, make sure that the main information will still be visible. Many colors are not distinguishable from one another when converted to black and white. A simple way to check this is to make a xerographic copy to see if the necessary distinctions between the different colors are still apparent.
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- To add lettering, it is best to use Helvetica or Arial (sans serif fonts).
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- Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file.
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- No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.
- Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.
- Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

Figure Placement and Size

- Figures should be submitted separately from the text, if possible.
- When preparing your figures, size figures to fit in the column width.
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In order to give people of all abilities and disabilities access to the content of your figures, please make sure that

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- Patterns are used instead of or in addition to colors for conveying information (colorblind users would then be able to distinguish the visual elements)
- Any figure lettering has a contrast ratio of at least 4.5:1

FIGURE CAPTION SHEET

The figure caption sheet contains a list of only the captions for all figures used. Center the label "Figure Captions" in uppercase and lowercase letters at the top of the page. Begin each caption entry flush left, and type the word "Figure", followed by the appropriate number and a period, all in italics. In the text of the caption (not italicized), capitalize only the first word and any proper nouns. If the caption is more than one line, double-space between the lines, and type the second and subsequent lines flush left. Table notes: Copyright permission footnotes for figures are typed as part of the figure caption.

- Each figure should appear on a separate page. The page where the figure is found should have the figure number and the word "top"[ie, Figure 1 top] typed above the figure. Figures or illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of arabic numerals. Figures may be embedded in the text of a Word or Wordperfect document. Electronic artwork submitted on disk may be in the TIFF, EPS or Powerpoint format (best is 1200 dpi for line and 300 dpi for half-tones and gray-scale art). Color art should be in the CYMK color space. Assistance will be provided by the system administrator if you do not have electronic files for figures; originals of artwork may be sent to the system administrator to be uploaded. *** After first mention in the body of the manuscript, a call-out for the correct placement of each figure should be included in brackets on a separate line within the text.

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