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**To cite this article:** Damian Santomauro, Jeanie Sheffield & Kate Sofronoff (2016): Investigations into emotion regulation difficulties among adolescents and young adults with autism spectrum disorder: A qualitative study, Journal of Intellectual & Developmental Disability, DOI: [10.3109/13668250.2016.1236240](https://doi.org/10.3109/13668250.2016.1236240)

**To link to this article:** <http://dx.doi.org/10.3109/13668250.2016.1236240>



Published online: 05 Oct 2016.



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ORIGINAL ARTICLE

## Investigations into emotion regulation difficulties among adolescents and young adults with autism spectrum disorder: A qualitative study

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### ABSTRACT

*Background* Emotion regulation difficulties have been associated with depression and anxiety in typically developing individuals. However, until recently, the impact of emotion regulation difficulties for adolescents and young adults with autism spectrum disorder (ASD) has received little attention. We investigated emotion regulation difficulties from the perspective of those who would experience the sequelae. This included parents, teachers, and psychologists.

*Method* Seven focus groups with parents, teachers, and psychologists, and 7 interviews with adolescents and young adults with ASD were conducted.

*Results* Across the groups, participants discussed their triggers of distressing emotions, difficulties with emotional awareness, emotion regulation strategies, and the consequences of their distressing emotions. Both depression and anxiety were perceived as the most experienced distressing issues with the greatest consequences.

*Conclusions* The implications of the themes revealed in the interviews and focus groups are discussed in light in previous literature and may help to inform future interventions.

### KEYWORDS

autism spectrum disorder; emotion regulation; depression; anxiety; focus groups; interviews; qualitative

### Introduction

Emotion regulation is the process responsible for identifying, monitoring, and modifying emotional reactions to emotional triggers and has been revealed to benefit interpersonal functioning, wellbeing, and financial success (Côté, Gyurak, & Levenson, 2010; Gross & John, 2003). However, difficulty with emotion regulation has been linked to mood disorders, such as depression and anxiety (Campbell-Sills, Barlow, Brown, & Hofmann, 2006; Dennis, 2007; Ehring, Tuschen-Caffier, Schnülle, Fischer, & Gross, 2010; Joormann & Gotlib, 2010). Furthermore, previous research has revealed increased rates of depression and anxiety in individuals with autism spectrum disorder (ASD; MacNeil, Lopes, & Minnes, 2009; White, Ollendick, & Bray, 2011; White, Oswald, Ollendick, & Scahill, 2009). Therefore the authors felt an intervention targeting emotion regulation skills for adolescents and young adults with ASD would be beneficial. As a first step to developing and testing this intervention, we aimed to explore emotion regulation in adolescents and young adults with ASD using a qualitative methodology.

Due to the novelty and encompassing nature of emotion regulation as a construct, researchers have highlighted the need for emotion regulation to be clearly

defined (Bridges, Denham, & Ganiban, 2004; Cole, Martin, & Dennis, 2004). Eisenberg and Spinrad (2004) defined emotion regulation as:

The process of initiating, avoiding, inhibiting, maintaining, or modulating the occurrence, form, intensity, or duration of internal feeling states, emotion-related physiological, attentional processes, motivational states, and/or the behavioral concomitants of emotion in the service of accomplishing affect-related biological or social adaptation or achieving individual goals. (p. 338)

This definition illustrates the complexity of emotion regulation as a construct. However, Bridges et al. (2004) discussed how emotion regulation should be associated with a subsequent decrease in the experience of the emotion. Some emotion regulation strategies may be ineffective in achieving this, and may in fact be counterproductive. A common example of an ineffective emotion regulation strategy is expressive suppression (Goldin, McRae, Ramel, & Gross, 2008; Roberts, Levenson, & Gross, 2008). Expressive suppression involves inhibiting the behavioural expression of an emotion (e.g., masking one's emotions). However, it often leads to no change in the experience of the emotion, and can even exacerbate the emotion (Roberts et al., 2008). Furthermore, frequent use of expressive suppression has

been associated with depression and anxiety (Campbell-Sills et al., 2006; Dennis, 2007; Ehring et al., 2010; Joormann & Gotlib, 2010), and seems to impact negatively on social interactions (Côté et al., 2010). Therefore, although strategies like expressive suppression may achieve a short-term goal, they may fail to regulate the experience of a distressing emotion, and may lead to unintended negative consequences for the individual. For this paper, such strategies are considered dysfunctional. Functional strategies, however, result in a reduced experience of the emotion, and tend not to be coupled with unintended negative consequences. A frequently researched functional strategy is cognitive reappraisal, which involves reinterpreting or reformulating the meaning of a situation, event, or stimuli to reduce the experience of an emotion (Banks, Eddy, Angstadt, Nathan, & Phan, 2007; Goldin et al., 2008). Cognitive reappraisal is considered a functional strategy because it tends to reduce the experience of the emotion, and is associated with better interpersonal functioning and wellbeing (Côté et al., 2010; Gross & John, 2003).

Until recently, investigations into emotion regulation in adolescents and young adults with ASD have been limited, with most of the research focused on children. For example, Konstantareas and Stewart (2006) exposed children with ASD and typically developing children to a mildly frustrating situation and observed their behaviour in response. Initially, the researchers gave the children a novel toy to play with, but then took the toy off the children abruptly. The researchers found that the children with ASD displayed less effective emotion regulation strategies compared to the typically developing children. Additionally, Ashburner, Ziviani, and Rodger (2010) revealed that teachers were more likely to report that their students with ASD had poorer emotion regulation skills than their typically developing students. However, in recent years there has been an increase in the volume of research targeting older individuals with ASD (Weiss, Thomson, & Chan, 2014). Samson, Huber, and Gross (2012) were the first to show that adults with ASD use fewer functional strategies, and more dysfunctional strategies, than typically developing adults. Although there is evidence to suggest emotion regulation difficulties may exist for adolescents and young adults with ASD, there has been minimal investigation on the impact of these difficulties from the perspective of those with ASD, or those who work or live with them.

A qualitative approach may be beneficial as a preliminary investigation into emotion regulation difficulties. This may provide insight into what potentially triggers emotions that adolescents and young adults find difficult to regulate, how emotion regulation difficulties affect their lives, and what strategies they use to try to regulate

their emotions. Qualitative methods are useful when the aims of a study are exploratory, and have been used in research on anxiety in children with ASD (Ozsivadjian, Knott, & Magiati, 2012), illustrating clinically useful information from the perspectives of the participants. In the current study, we aimed to explore the potential triggers, emotion regulation strategies, consequences, and any additional issues brought up through focus groups and interviews with a range of people who have experience with the emotion regulation of adolescents and young adults with ASD. These include parents of adolescents and young adults with ASD, psychologists who have adolescents and young adults with ASD as clients, teachers and teacher aides who work with students with ASD, and adolescents and young adults themselves.

## Method

### Design

For this study we adopted an exploratory qualitative design through a series of focus groups and interviews.

### Participants

In total there were 33 participants included in the thematic analysis. The sample included nine parents, 13 teachers, teacher aides, and special education teachers, four psychologists, and seven adolescents and young adults with ASD. The mean age of the children the parents represented was 15.43 years ( $SD = 1.99$ , range: 13–19), and all were male. The mean age of the participants with ASD was 20.71 ( $SD = 3.09$ ), with ages ranging between 14 and 23. One of the seven participants with ASD was female. Five participants had a diagnosis of Asperger disorder, one had a diagnosis of high-functioning autism, and one had a diagnosis of pervasive developmental disorder not otherwise specified. Recruitment for these focus groups was achieved through advertisements placed in the newsletter of The University of Queensland, Brisbane, Australia, a support association's newsletter, emails sent out to the mail list of the support association, and word of mouth. Diagnoses of ASD for the interview participants and the children of the focus group parents were obtained during the screening process via interview. To be eligible, participants required a diagnosis of an ASD from a medical practitioner, paediatrician, psychiatrist, psychologist, or multidisciplinary team to participate. Recruitment continued until it was evident that additional focus groups and interviews were no longer revealing novel information (i.e., until data saturation was achieved). Written informed consent was obtained from all participants (including parental

consent where appropriate), and ethical approval was obtained from the School of Psychology at The University of Queensland (clearance number 11-PSYCH-PHD-44-JJ).

### Procedure

Three parent focus groups were conducted with the nine parents. Two of the parent focus groups were conducted in a private room at The University of Queensland. The third parent focus group was conducted in a high school attended by their children with ASD. Three focus groups were also conducted involving 13 teachers, teacher aides, and special education teachers, who worked with adolescent students with ASD. A final focus group involving four psychologists who specialise in ASD was also conducted. The focus groups involving teachers and psychologists were held at locations of convenience to the participants (generally at their workplace).

Due to difficulty recruiting participants with ASD who were willing to participate in the focus group setting, seven individual interviews were conducted with adolescents and young adults with ASD. The interviews were conducted in a place of convenience for them, over the phone, or via Skype. All focus groups and interviews were audio-recorded, with participant consent, and then transcribed for analysis. Participants were invited to provide their contact details if they wished to be contacted again about the research project.

### Interview process

The interviewer (the first author) asked participants questions relating to cues they used to identify emotions, how emotion regulation difficulties have affected their lives, and what strategies they have used to regulate their emotions (both successful and unsuccessful). The interviewer used an interview guide to promote discussion (see Appendix), with questions reworded to reference the individual with ASD when required (e.g., your child, your student). Therefore the interviews and focus groups were semistructured.

### Data analysis

The interviews were transcribed and the transcriptions were then reviewed for errors before being imported into NVivo 9 (QSR International Pty Ltd, 2010), a qualitative data analysis program that allows users to easily review transcripts, code text, and form themes. In this program the transcriptions were then reviewed for thematic analysis following the guide published by Braun and Clarke (2006), which describes six steps for

conducting thematic analysis. The first step involved familiarising oneself with the data. Familiarity was achieved as the recordings were transcribed, read, and analysed by the interviewer (the first author). The second step involved generating initial codes for the data. Semantic content perceived as important to the research questions was given initial codes. Step three involved searching for themes among the initial codes. Once all the transcriptions had been coded, they were viewed from a broader perspective and collated into potentially meaningful themes. Potential themes and their coded content were reviewed once again in step four for appropriateness and coherence. At this stage, many potential themes that were similar were designated as subthemes under the umbrella of an overarching theme. During step five, each theme was reviewed again and named based on the content of that theme. The final step was to write up the analysis and conduct member checking. A draft of the results and discussion for this paper was sent to participants who opted to provide feedback. Upon review of the transcripts it was evident that the emerging themes were consistent across the groups. Therefore in the final analysis the data were pooled. Small differences between the groups are discussed in detail as follows.

### Results

From the thematic analysis of the transcripts, there is evidence to suggest that emotion regulation is an ongoing issue for adolescents and young adults with ASD, with participants reporting disturbances from feelings of depression, anxiety, anger, and loneliness. Furthermore, participants discussed the *triggers of distressing emotions*, *difficulties with emotional awareness*, *emotion regulation strategies*, and the *consequences of distressing emotions*. These themes, their subthemes, and example quotations can be seen across Tables 1–4. Note that names have been changed to ensure confidentiality of the participants.

#### Triggers of distressing emotions

Participants in the focus groups and interviews all reported a variety of triggers that are typically associated with distressing emotions. There were six subthemes that emerged from the data. One of these themes was *social triggers*, where every group of participants described bullying and ostracism as major triggers of negative emotions, which typically happened while the individuals with ASD were at school. Participants also talked about general social triggers of anxiety, such as having to complete social tasks (e.g., a mock interview for a school assignment), or even engaging socially with

**Table 1.** The overarching theme of Triggers of Emotions and its subthemes.

Theme	Subtheme	Example quotes
Triggers of emotions	Social triggers	"... people did keep an eye out for me, yeah; I was the thing to be bullied ..." (Liz, 21-year-old female with ASD)
	School or employment	"Patrick can become worried about homework, exams ... he'll be quite stressed ... you can't reason with him, so he has this overriding anxiety." (Hayley, mother of a 19-year-old boy with ASD)
	Sensory triggers	"... cannot go to swimming carnivals, cannot go to sporting carnivals ... behaviour will deteriorate for 10 weeks ... because it's just he's had an overload." (David, father of a 16-year-old boy with ASD)
	Biological	"And I found the underweight is really detrimental to mood ... they are not getting enough nutrition, or there's sensory issues, they can't chew, eat comfortably ... we're not going to get very far on an anxiety management programme until the weight comes up and he's stabilised." (Emma, clinical psychologist specialising in ASD)
	Change	"I told him he was going to be taken out of the Wednesday group to go into the Friday group and the chairs started flying everywhere ..." (Ray, special education teacher at a state high school)
	Fear of failure	"A lot of the times I get scared that I'm going to fail ... say it's a job that I'm going for ... I'll automatically think that I've failed ... my anxiety builds up from there." (Corey, 21-year-old male with ASD)

**Table 2.** The overarching theme of Difficulties with Emotional Awareness and its subthemes.

Theme	Subtheme	Example quotes
Difficulties with emotional awareness	Alexithymia	"He doesn't know what his feelings are, he cannot articulate how he feels ... if there's something troubling him and you ask him he will say nothing because he doesn't articulate if there is something wrong ..." (Kate, mother of a 16-year-old male with ASD)
	Need for external notification	"So if this young lady is behaving in a certain way and people run away, and she's angry and people do this, then she'll label it." (Grace, head of special education services at a state high school)
	Misidentification	"... there probably are some that attempt to read those cues themselves ... but then some of it is not quite accurate." (Charles, special education teacher at a state high school)
	Emotional awareness threshold	"... he doesn't identify what emotions he's having, unless it's in the extreme ... but even then that's a limited understanding." (Anthony, father of a 14-year-old male with ASD)

**Table 3.** The overarching theme of Emotion Regulation Strategies and its subthemes.

Theme	Subtheme	Example quotes
Emotion regulation strategies	Cognitive	"... if it's something negative about me personally I just think about positive things about myself." (Fred, 21-year-old male with ASD)
	Pre-emptive	"... it's a matter of looking ahead, seeing what may cause problems and trying to stop it before it happens." (Liz, 21-year-old female with ASD)
	Behavioural	"... if I'm having a bad day, I'll go home. If I'm at a social occasion that I suddenly can't bear to be around anymore, I'll leave. I'll retreat is sort of the general strategy." (Max, 23-year-old male with ASD)
	External support	"... I generally go online ... the thing to do is talk to someone because if you just sit there then nothing much is going to change, it's getting yourself online to talk to people ..." (Liz, 21-year-old female with ASD)
	Suppression	"They suppress it, there's no doubt, and they're aware of it, but they do not know how to deal with that anger that builds up so they suppress it, but it's really just a volcano waiting to happen." (Edward, special education teacher at a state high school)
	Self-harm	"There is a risk of suicide in this population ... so you can get those as young adults, 'This is it, I'm an adult now, it's not worked out, it'll never work out, can't stand the pain, I'm out of here.'" (Adrian, clinical psychologist specialising in ASD)
	Drugs	"I've found it's the only thing that ... I can escape and just sort my own problems out with ... I've never had a medication that's done that before you know?" (Corey, 21-year-old male with ASD)

**Table 4.** The overarching theme of Consequences of Distressing Emotions and its subthemes.

Theme	Subtheme	Example quotes
Consequences of distressing emotions	Academic consequences	"... being depressed or anxious ... would stop me from doing something that was necessary like doing an assignment ... and I wouldn't do it until the last minute and then it just wouldn't nearly be as good as it could have been." (Max, 23-year-old male with ASD)
	Social consequences	"... being depressed can really screw you over in a relationship and so can being anxious ... my first girlfriend actually broke up with me for precisely that reason ... they certainly can have an effect on dealing with people ..." (Max 23-year-old male with ASD)
	Consequences for others	"... for whatever reason they'll feel emotionally, physically, ... backed into a corner, and bang it explodes into a physical nature ... I mean we have holes put in walls and windows broken ..." (Frank, special education teacher at a state high school)
	Worry of long-term consequences	"... remaining jobless, remaining relationship-less, with all of the problems that that can bring up in terms of depression, and losing touch with reality, being too isolated ... and self harm issues." (Emma, clinical psychologist specialising in ASD)



others. Major social events such as family gatherings and school events were still viewed by parents as triggers for emotional distress, and participants with ASD reported many miscellaneous social issues as triggers of their emotions (e.g., friendship issues, new social situations).

A second trigger subtheme that emerged from the data was *school or employment*. All groups spoke about how assessment tasks were extremely anxiety provoking for individuals with ASD. The behaviours of leaving assignments or tasks to the last minute and poor organisational skills were often referred to as causes of stressors in the school and work environment. Bullying that occurred in both school and the workplace was also mentioned as an emotional trigger of anxiety, depression, and anger. All groups also talked about clashes between teachers and students with ASD as another trigger, and the misperception of the student with ASD “just being naughty” by both teachers and other parents as an underlying factor in an unsupportive environment.

A third major trigger subtheme emerged that reflected *sensory triggers*, where participants discussed negative emotional responses to loud noises, tactile sensations, light, and smells. This subtheme was related to both social and school or employment subthemes, as many of the sensory triggers occurred in the school or workplace environment, or were due to the proximity of a large number of people (e.g., a noisy classroom). It was also related to a fourth subtheme of triggers, which was *biological*. Some parents talked about how their adolescents with ASD were very picky eaters due to sensory issues. Hunger was seen as a trigger of negative emotions, as was lack of sleep. The last two subthemes of emotional triggers were *change* and *fear of failure*. Big changes, such as moving houses and divorce of parents, were seen as triggers of negative emotions, as they would likely be for typically developing children. In addition, however, there were changes from routine, such as holidays, school camps, and school sporting events, and seemingly minute deviations from routine, such as a change in their class timetable. The participants with ASD themselves frequently mentioned a trigger for their anxiety being a fear of failure, or a fear of not reaching their own expectations or the expectations of others. These included fear of not achieving good grades at school, of not having enough money to achieve what they would like, of disappointing a bank or organisation, and of not being prepared for a situation.

### Difficulties with emotional awareness

Following emotional triggers, participants in the focus groups and interviews often talked about the difficulties with emotional awareness. Again, several subthemes

emerged from the data. The first was *alexithymia*, which is the difficulty in recognising and labelling emotions. Alexithymia was mainly discussed by parents, teachers, and psychologists, describing the difficulties adolescents and young adults with ASD face when it comes to articulating their emotions. Participants also discussed the *need for external notification*, where they would rely on external rather than internal cues or explicit external notification in order to be able to appropriately label what they were feeling. External cues included other people’s behaviours, feedback from others, and the monitoring of their own involuntary behaviour (such as observing that they are being aggressive or their hands are shaking). One participant even told of a student of hers who could not identify her own anger until other students began to run away from her (see Table 2). The most frequently given example of external notification was from a counsellor or friend verbally informing them what they may be feeling, and helping them explicitly learn each emotion. This may be a potential tool for any intervention intending to improve emotion regulation skills in adolescents and young adults with ASD.

A third subtheme was *misidentification of emotions*. Participants often discussed how when the adolescents and young adults with ASD attempt to recognise and label their emotions, they often label them incorrectly. Another issue that all groups of participants discussed was the existence of an *emotional awareness threshold*. Participants often described how the adolescents and young adults with ASD were not aware of their emotions at all until the emotion became quite extreme. Participants frequently stated that their emotions are “either on or off.” Parents and teachers discussed how a negative emotional reaction from an adolescent or young adult with ASD might be caused from something that happened much earlier in the day, which had been building until it reached the awareness threshold. Adolescents and young adults confirmed that they are often not aware of the triggers of their emotions.

### Emotion regulation strategies

Once awareness of the emotions had been established, participants talked about how adolescents and young adults with ASD tried to regulate their distressing emotions. A variety of emotion regulation strategies were discussed, which formed seven subthemes: *cognitive*, *pre-emptive*, *behavioural*, *external support*, *suppression*, *self-harm*, and *drugs* (see Table 3).

In the cognitive category, participants with ASD described how they would try to rationalise their emotions to deal with them, think of something other than what was causing their emotion, and enter their

own fantasy world. Moreover, participants discussed pre-emptive strategies, which aimed to avoid the known triggers of negative emotions. These attempts to avoid triggers included using organisational skills such as keeping diaries and writing lists and schedules, especially with school assessment or work. In a similar manner, planning ahead for potential triggers was discussed, such as school or social events (camps, holidays, driving tests), where parents particularly talked about providing mental and emotional preparation for events, and having a plan for when an emotional meltdown occurs. The most prominent subtheme across all groups, however, was behavioural strategies, with the most discussed technique being avoidance and isolation.

Another common behavioural strategy was physical activity. Many participants with ASD and their parents reported that physical exercise and going for walks really helped them manage their distressing emotions. Relaxation was another method used to cope with emotions, such as meditating or listening to music. Finally, pursuing interests was a strategy that emerged from the data. These interests included train spotting, reading specific books, watching movies, and playing computer or video games, although it was reported from the participants with ASD that books and playing computer or video games can assist them to enter their fantasy world. Participants with ASD, parents, and teachers also discussed the role of the online community as social support for adolescents and young adults with ASD, where participants sought social support via gaming platforms such as Xbox Live, World of Warcraft, and from general online social communities.

External support was another subtheme of emotion regulation strategies, where adolescents and young adults with ASD sought social support in order to cope with their emotions. In addition to the online communities, participants sought social support from parents, teachers, and friends. This social support typically consisted of just talking over the emotional issue, or general social interaction in order to fend off feelings of depression. Another source of external support was some form of professional help, which included seeing a psychiatrist, a psychologist, or a counsellor.

Many participants reported that adolescents and young adults with ASD also tend to use dysfunctional emotion regulation strategies, such as suppression and self-harm. Participants often discussed the use of suppression to cope with their emotions. They discussed how although they still feel the emotion, they try to avoid all behavioural output of that emotion, in the hope of hiding or masking it from others. This was often displayed through withdrawal, but frequently led to outbursts at a later point in time once the trigger of

the emotion had long past. Self-harm was also described as an emotion regulation strategy by some participants. Methods discussed were cutting, severe skin picking, and suicidal ideation. Every participant with ASD reported that they had experienced suicidal thoughts.

Lastly, the use of drugs (legal or otherwise) by participants with ASD was discussed. Of the 14 participants with ASD represented in this study (either by their parents or representing themselves), six reported taking medication in order to help regulate their emotions; most commonly this was antidepressants. Three participants claimed to have used marijuana to help them with their emotions. One said it helped him with sensory triggers, but the other two said it helped them with anxiety.

### Consequences of distressing emotions

The final theme that emerged from the data was *consequences of emotions*, where participants discussed how a difficulty in regulating emotions had a negative effect on their lives. Four subthemes emerged from the data: *academic consequences*, *social consequences*, *consequences for others*, and *worry of long-term consequences*. Participants frequently discussed how their difficulty to regulate emotions had a negative impact on their studies in school and university. Typically, this was either due to procrastination as a result of severe anxiety, or lack of motivation as a result of depression. Additionally, teachers explained that if a student with ASD had an emotional episode at school, the remainder of the school day for that student was generally wasted.

Participants also discussed the social consequences of the emotion regulation difficulties. Consequences included a reduced capacity to form strong relationships with others due to avoidance and isolation emotion regulation strategies, from hiding or suppressing their emotions from others, and from others generally not liking their emotional behaviours. Participants also discussed how emotional behaviours had a negative effect on the people around them. Verbal harassment and physical altercations were the most common topics of discussion from the focus groups and interviews in regard to consequences for others.

The last subtheme that emerged from the analysis of the transcripts was worry about long-term consequences. All groups of participants expressed these worries. Parents expressed concerns for their children's employment options due to their inability to regulate their emotions, and their ability to live independently. Teachers and psychologists also discussed concerns about employment, but focused more on the impact the adolescents' emotions will have on their ability to form and

maintain supportive relationships as adults. The potential for suicide was also an issue addressed in the psychologist focus group, and was identified as a fear for a participant with ASD. Participants with ASD were also concerned about the effects of their emotions on their employment, and their ability to form and hold relationships, and were also concerned about the long-term effects their emotions have on their physical health.

### Participant feedback

To check the validity of the above findings, 20 participants who had provided contact details were contacted for feedback. Two participants were unavailable for contact, two declined to provide feedback, and 16 agreed to provide feedback. A draft of the results and discussion of this study was sent to these participants, and all participants agreed that it accurately reflected their experience.

### Discussion

In this study we aimed to investigate the extent to which emotion regulation was an issue during adolescence and young adulthood in individuals with ASD, and to obtain insight from different perspectives. Participants discussed the triggers of distressing emotions, difficulties with emotional awareness, emotion regulation strategies, and the consequences of distressing emotions. Several of the endorsed triggers of distressing emotions were unsurprising; for example, both bullying and ostracism have previously been documented in children with ASD (Sofronoff, Dark, & Stone, 2011; Wainscot, Naylor, Sutcliffe, Tantam, & Williams, 2008). Additionally, given that ASD is characterised by social deficits, it is likely that social situations for individuals with ASD would lead to emotions such as social anxiety (Bellini, 2004; Kuusikko et al., 2008). However, there were several triggers of distressing emotions that have received little attention, such as biological triggers and fear of failure. Research is mixed as to whether children with high food refusal also show reduced nutrition (Bandini et al., 2010; Cermak, Curtin, & Bandini, 2010; Hare, Jones, & Evershed, 2006). In cases where nutrition and hunger is a concern, it is plausible that these may lead to distressing emotions or at least be a catalyst for another trigger. Furthermore, sleep disturbances in children with ASD have been documented in previous studies (e.g., Richdale, 1999), and although questionnaire reports of sleep disturbances in adolescents and young adults with ASD give the impression of improvement from childhood, physiological measures indicate sleep disturbances are still an issue for adolescents and young adults with ASD (Godbout, Bergeron, Limoges, Stip, & Mottron, 2000; Øyane &

Bjorvatn, 2005). Research with children with ASD illustrates greater fears of situational factors rather than fear of failure (Evans, Canavera, Kleinpeter, Maccubbin, & Taga, 2005; Matson & Love, 1990). However, as participants with ASD develop into their adolescence and young adulthood, their hierarchy of fears may change.

Discussions from the focus groups and interviews provided insight for the need of an intervention targeting emotion regulation difficulties. It is evident from the difficulties in emotional awareness theme that an intervention targeting emotion regulation difficulties would need a significant focus on improving one's ability to identify and label one's own emotions. Alexithymia has been identified in both children and adults with ASD in previous research (Berthoz & Hill, 2005; Rieffe, Meerum Terwogt, & Kotronopoulou, 2007; Silani et al., 2008). As one of the first steps in consciously modifying an emotion is identifying the emotion, this finding suggests that an intervention targeting emotion regulation in adolescents and young adults with ASD should also teach skills to identify one's emotions. Furthermore, these findings highlight emotion regulation strategies that adolescents and young adults with ASD, their parents, teachers, and psychologists endorse to be successful.

This study also highlighted the potential consequences of emotion regulation difficulties if they are not addressed. Academic consequences have been illustrated in previous literature; however, this is typically attributed to executive functioning difficulties and not to emotion regulation difficulties (e.g., Zingerevich & LaVesser, 2009). Furthermore, evidence for social consequences has been found in studies by Koning and Magill-Evans (2001) and Wainscot et al. (2008), which both suggested that adolescents with ASD had significantly fewer friends compared to typically developing adolescents. However, the current study sheds light on an alternative contributing cause, as, typically, social consequences have been solely attributed to social skills difficulties and not emotion regulation difficulties. Lastly, participants expressed concerns for the prospects of adolescents and young adults with ASD and emotion regulation difficulties, namely, employment prospects and concerns for suicidality.

These worries are legitimate as the rates of employment for adults with ASD are low, with some estimates ranging between 2% and 35% (Barnard, Harvey, Potter, & Prior, 2001; Benz, Lindstrom, & Yovanoff, 2000; Billstedt, Gillberg, & Gillberg, 2005; Engström, Ekström, & Emilsson, 2003). Suicidality is also a very legitimate concern, as the prevalence of suicidal behaviour among adolescents and young adults with ASD ranges from 7% to 42% (Hannon & Taylor, 2013) as opposed to 4% to 8% in typically developing adolescents and young adults



(Cash & Bridge, 2009; Gmitrowicz, Szymczak, Kotlicka-Antczak, & Rabe-Jabłońska, 2003; Resch, Parzer, & Brunner, 2008).

### Limitations and future directions

Although the themes that emerged from the data were endorsed by many participants of the focus groups, it is important to note that there is great heterogeneity within this spectrum of conditions. Even the most popularly endorsed themes were not endorsed by every participant. It is also difficult to distinguish between themes that are specific to those with ASD and those that would be shared with typically developing adolescents and young adults. The current findings would therefore be enhanced with a comparative study with typically developing adolescent participants and adolescents with emotion regulation difficulties but without ASD. It might be the case that the same issues occur for adolescents with ASD but at a higher rate. The relatively small sample size in this study may limit the scope of the results, and the experience of participants who chose to participate may not reflect the experience of participants who chose not to participate. However, recruitment for participants ceased once data saturation was achieved. Additionally, an independent crosscheck of the transcriptions and emergent themes was not conducted. Despite this, all 16 participants who were willing to provide feedback on the themes agreed that the themes accurately reflected their experience. It is also important to note that the clinical diagnoses of the participants were reported during the screening process and were not verified by a gold standard diagnostic tool. It was outside the scope of this study to include diagnostic assessment. However, to the authors' knowledge, this study is the first qualitative study investigating emotion regulation specifically in adolescents and young adults with ASD. Given the novelty of the study, the authors of this paper believe this is a notable but worthwhile compromise.

Now that the qualitative method has revealed common triggers of distressing emotions, barriers to emotion regulation, and successful emotion regulation strategies for adolescents and young adults with ASD, the next step is to develop and trial an intervention that incorporates the information revealed in the current study. Following this qualitative investigation, an intervention was developed to target emotion regulation difficulties in adolescents with autism spectrum conditions. A randomised controlled trial of a group cognitive behavioural intervention was conducted (Santomauro, Sheffield, & Sofronoff, 2016). This investigation addressed the triggers and barriers revealed in the current study, and

took full advantage of strategies revealed to be successful for adolescents and young adults with ASD.

### Disclosure statement

No potential conflict of interest was reported by the authors.

### Funding

This project was conducted as part of Damian Santomauro's PhD dissertation, which was funded by an Australian Postgraduate Award scholarship. There are no restrictions imposed on the free access to, or publication of, this research project.

### References

- Ashburner, J., Ziviani, J., & Rodger, S. (2010). Surviving in the mainstream: Capacity of children with autism spectrum disorders to perform academically and regulate their emotions and behavior at school. *Research in Autism Spectrum Disorders*, 4, 18–27. doi:10.1016/j.rasd.2009.07.002
- Bandini, L. G., Anderson, S. E., Curtin, C., Cermak, S., Evans, E. W., Scampini, R., ... Must, A. (2010). Food selectivity in children with autism spectrum disorders and typically developing children. *The Journal of Pediatrics*, 157, 259–264. doi:10.1016/j.jpeds.2010.02.013
- Banks, S. J., Eddy, K. T., Angstadt, M., Nathan, P. J., & Phan, K. L. (2007). Amygdala-frontal connectivity during emotion regulation. *Social Cognitive and Affective Neuroscience*, 2, 303–312. doi:10.1093/scan/nsm029
- Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). *Ignored or ineligible: The reality for adults with autism spectrum disorders*. London, UK: The National Autistic Society.
- Bellini, S. (2004). Social skills deficits and anxiety in high-functioning adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 19, 78–86. doi:10.1177/10883576040190020201
- Benz, M. R., Lindstrom, L., & Yovanoff, P. (2000). Improving graduation and employment outcomes of students with disabilities: Predictive factors and student perspectives. *Exceptional Children*, 66, 509–529.
- Berthoz, S., & Hill, E. L. (2005). The validity of using self-reports to assess emotion regulation abilities in adults with autism spectrum disorder. *European Psychiatry*, 20, 291–298. doi:10.1016/j.eurpsy.2004.06.013
- Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, 35, 351–360. doi:10.1007/s10803-005-3302-5
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. doi:10.1191/1478088706qp0630a
- Bridges, L. J., Denham, S. A., & Ganiban, J. M. (2004). Definitional issues in emotion regulation research. *Child Development*, 75, 340–345. doi:10.1111/j.1467-8624.2004.00675.x
- Campbell-Sills, L., Barlow, D. H., Brown, T. A., & Hofmann, S. G. (2006). Acceptability and suppression of negative

- emotion in anxiety and mood disorders. *Emotion*, 6, 587–595. doi:10.1037/1528-3542.6.4.587
- Cash, S. J., & Bridge, J. A. (2009). Epidemiology of youth suicide and suicidal behavior. *Current Opinion in Pediatrics*, 21, 613–619. doi:10.1097/MOP.0b013e32833063e1
- Cermak, S. A., Curtin, C., & Bandini, L. G. (2010). Food selectivity and sensory sensitivity in children with autism spectrum disorders. *Journal of the American Dietetic Association*, 110, 238–246. doi:10.1016/j.jada.2009.10.032
- Cole, P. M., Martin, S. E., & Dennis, T. A. (2004). Emotion regulation as a scientific construct: Methodological challenges and directions for child development research. *Child Development*, 75, 317–333. doi:10.1111/j.1467-8624.2004.00673.x
- Côté, S., Gyurak, A., & Levenson, R. W. (2010). The ability to regulate emotion is associated with greater well-being, income, and socioeconomic status. *Emotion*, 10, 923–933. doi:10.1037/a0021156
- Dennis, T. A. (2007). Interactions between emotion regulation strategies and affective style: Implications for trait anxiety versus depressed mood. *Motivation and Emotion*, 31, 200–207. doi:10.1007/s11031-007-9069-6
- Ehring, T., Tuschen-Caffier, B., Schnülle, J., Fischer, S., & Gross, J. J. (2010). Emotion regulation and vulnerability to depression: Spontaneous versus instructed use of emotion suppression and reappraisal. *Emotion*, 10, 563–572. doi:10.1037/a0019010
- Eisenberg, N., & Spinrad, T. L. (2004). Emotion-related regulation: Sharpening the definition. *Child Development*, 75, 334–339. doi:10.1111/j.1467-8624.2004.00674.x
- Engström, I., Ekström, L., & Emilsson, B. (2003). Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. *Autism*, 7, 99–110. doi:10.1177/1362361303007001008
- Evans, D. W., Canavera, K., Kleinpeter, F. L., Maccubbin, E., & Taga, K. (2005). The fears, phobias and anxieties of children with autism spectrum disorders and Down syndrome: Comparisons with developmentally and chronologically age matched children. *Child Psychiatry and Human Development*, 36, 3–26. doi:10.1007/s10578-004-3619-x
- Gmitrowicz, A., Szymczak, W., Kotlicka-Antczak, M., & Rabe-Jabłońska, J. (2003). Suicidal ideation and suicide attempt in Polish adolescents: Is it a suicidal process? *International Journal of Adolescent Medicine and Health*, 15, 113–124. doi:10.1515/IJAMH.2003.15.2.113
- Godbout, R., Bergeron, C., Limoges, E., Stip, E., & Motttron, L. (2000). A laboratory study of sleep in Asperger's syndrome. *NeuroReport*, 11, 127–130. doi:10.1097/00001756-200001170-00025
- Goldin, P. R., McRae, K., Ramel, W., & Gross, J. J. (2008). The neural bases of emotion regulation: Reappraisal and suppression of negative emotion. *Biological Psychiatry*, 63, 577–586. doi:10.1016/j.biopsych.2007.05.031
- Gross, J. J., & John, O. P. (2003). Individual differences in two emotion regulation processes: Implications for affect, relationships, and well-being. *Journal of Personality and Social Psychology*, 85, 348–362. doi:10.1037/0022-3514.85.2.348
- Hannon, G., & Taylor, E. P. (2013). Suicidal behaviour in adolescents and young adults with ASD: Findings from a systematic review. *Clinical Psychology Review*, 33, 1197–1204. doi:10.1016/j.cpr.2013.10.003
- Hare, D. J., Jones, S., & Evershed, K. (2006). A comparative study of circadian rhythm functioning and sleep in people with Asperger syndrome. *Autism*, 10, 565–575. doi:10.1177/1362361306068509
- Joormann, J., & Gotlib, I. H. (2010). Emotion regulation in depression: Relation to cognitive inhibition. *Cognition and Emotion*, 24, 281–298. doi:10.1080/02699930903407948
- Koning, C., & Magill-Evans, J. (2001). Social and language skills in adolescent boys with Asperger syndrome. *Autism*, 5, 23–36. doi:10.1177/1362361301005001003
- Konstantareas, M. M., & Stewart, K. (2006). Affect regulation and temperament in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 36, 143–154. doi:10.1007/s10803-005-0051-4
- Kuusikko, S., Pollock-Wurman, R., Jussila, K., Carter, A. S., Mattila, M.-L., Ebeling, H., ... Moilanen, I. (2008). Social anxiety in high-functioning children and adolescents with autism and Asperger syndrome. *Journal of Autism and Developmental Disorders*, 38, 1697–1709. doi:10.1007/s10803-008-0555-9
- MacNeil, B. M., Lopes, V. A., & Minnes, P. M. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 3, 1–21. doi:10.1016/j.rasd.2008.06.001
- Matson, J. L., & Love, S. R. (1990). A comparison of parent-reported fear for autistic and nonhandicapped age-matched children and youth. *Australia and New Zealand Journal of Developmental Disabilities*, 16, 349–357. doi:10.1080/07263869000034161
- Øyane, N. M. F., & Bjorvatn, B. (2005). Sleep disturbances in adolescents and young adults with autism and Asperger syndrome. *Autism*, 9, 83–94. doi:10.1177/1362361305049031
- Ozsivadjian, A., Knott, F., & Magiati, I. (2012). Parent and child perspectives on the nature of anxiety in children and young people with autism spectrum disorders: A focus group study. *Autism*, 16, 107–121. doi:10.1177/1362361311431703
- QSR International Pty Ltd. (2010). NVivo qualitative data analysis software (Version 9) [Computer software]. Melbourne, Australia: Author.
- Resch, F., Parzer, P., & Brunner, R., & the BELLA study group. (2008). Self-mutilation and suicidal behaviour in children and adolescents: Prevalence and psychosocial correlates: Results of the BELLA study. *European Child & Adolescent Psychiatry*, 17(Suppl. 1), 92–98. doi:10.1007/s00787-008-1010-3
- Richdale, A. L. (1999). Sleep problems in autism: Prevalence, cause, and intervention. *Developmental Medicine & Child Neurology*, 41, 60–66. doi:10.1111/j.1469-8749.1999.tb00012.x
- Rieffe, C., Meerum Terwogt, M., & Kotronopoulou, K. (2007). Awareness of single and multiple emotions in high-functioning children with autism. *Journal of Autism and Developmental Disorders*, 37, 455–465. doi:10.1007/s10803-006-0171-5
- Roberts, N. A., Levenson, R. W., & Gross, J. J. (2008). Cardiovascular costs of emotion suppression cross ethnic lines. *International Journal of Psychophysiology*, 70, 82–87. doi:10.1016/j.ijpsycho.2008.06.003
- Samson, A. C., Huber, O., & Gross, J. J. (2012). Emotion regulation in Asperger's syndrome and high-functioning autism. *Emotion*, 12, 659–665. doi:10.1037/a0027975
- Santomauro, D., Sheffield, J., & Sofronoff, K. (2016). Depression in adolescents with ASD: A pilot RCT of a group intervention. *Journal of Autism and Developmental Disorders*, 46, 572–588. doi:10.1007/s10803-015-2605-4

- Silani, G., Bird, G., Brindley, R., Singer, T., Frith, C., & Frith, U. (2008). Levels of emotional awareness and autism: An fMRI study. *Social Neuroscience*, 3, 97–112. doi:10.1080/17470910701577020
- Sofronoff, K., Dark, E., & Stone, V. (2011). Social vulnerability and bullying in children with Asperger syndrome. *Autism*, 15, 355–372. doi:10.1177/1362361310365070
- Wainscot, J. J., Naylor, P., Sutcliffe, P., Tantam, D., & Williams, J. V. (2008). Relationships with peers and use of the school environment of mainstream secondary school pupils with Asperger syndrome (high-functioning autism): A case-control study. *International Journal of Psychology and Psychological Therapy*, 8, 25–38.
- Weiss, J. A., Thomson, K., & Chan, L. (2014). A systematic literature review of emotion regulation measurement in individuals with autism spectrum disorder. *Autism Research*, 7, 629–648. doi:10.1002/aur.1426
- White, S. W., Ollendick, T. H., & Bray, B. C. (2011). College students on the autism spectrum: Prevalence and associated problems. *Autism*, 15, 683–701. doi:10.1177/1362361310393363
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review*, 29, 216–229. doi:10.1016/j.cpr.2009.01.003
- Zingerevich, C., & LaVesser, P. D. (2009). The contribution of executive functions to participation in school activities of children with high functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, 3, 429–437. doi:10.1016/j.rasd.2008.09.002

## Appendix

### Interview guide.

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1. Do you believe that you have difficulties managing your emotions?
  2. How do you know or recognise what you are feeling? Do you ever have trouble with this?
  3. What kinds of emotions do you not like feeling or find unpleasant?
  4. How do you know when you are feeling these?
  5. When you are experiencing a negative emotion and are having trouble or can't change it, how long does this experience typically last?
  6. How bad does it feel? On a scale of 1 to 10 (with 1 not bad and 10 it feels unbearable)?
  7. How do you behave when you are feeling upset, angry, or anxious? What sorts of things do you do?
  8. What typically happens after you behave that way?
  9. How does this behaviour affect your relationships with others?
  10. What do other people say about your trouble with your emotions? Has anyone ever suggested you have problems with your emotions?
  11. Does it affect your study or employment? If so, how?
  12. When do you think these problems with your emotions tend to occur? Are there any specific events or cues that can trigger a negative emotion?
  13. When did you first become aware of your problems with emotions?
  14. How long has it been a problem? Has it affected you your whole life or did it start more recently? Was there anything that started it?
  15. Do your emotions stop you from doing the things you want to do?
  16. Are you aware of any long-term effects of your difficulties with emotions?
  17. What do you do on a day-to-day basis to try to feel better?
  18. What do you do to try to change what you are feeling?
  19. Have you participated in any interventions before to deal with this problem?
  20. Do you take any medications to help you with this problem?
  21. Do you use any substances such as drugs, tobacco, or alcohol to help you with this problem?
  22. What do you think could help you try to manage your feelings?
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