



Self-Compassion in Mothers of Children with Autism Spectrum Disorder: A Qualitative Analysis

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Abstract

Emerging quantitative research found self-compassion to be a unique predictor of parental stress in parents of children with ASD above other predictors. However, research on the lived experience of self-compassion in families of children with ASD is limited. Using a qualitative thematic analysis approach, 19 mothers of children with ASD with a mean age of 39.19 years ($SD = 3.56$, $Range = 31.00–50.00$ years) were interviewed about their lived experiences of stress and self-compassion. Themes derived from interviews include: the impact and causes of stress, benefits of self-compassion, barriers to self-compassion, and aids to self-compassion. The findings deepen our understanding of the experience of self-compassion in this population. Limitations and future directions are discussed.

Keywords Qualitative · Self-compassion · Parenting · Mothers of children with ASD · Parent stress

Introduction

Autism spectrum disorder is characterised by persistent impairments in social interactions and communication across different contexts, as well as restricted, repetitive behaviour, activities, or interests (American Psychiatric Association 2013). ASD is a neurodevelopmental disorder affecting 0.74% of children under the age of 7 in Australia (Bent et al. 2015) or approximately one in 160 children more globally (Elsabbagh et al. 2012). Parents of children with ASD report higher levels of stress than parents of typically developing children, children with intellectual disabilities,

children with Down syndrome, children with ADHD, and children with cystic fibrosis (Abbeduto et al. 2004; Baker-Ericzén et al. 2005; Bouma and Schweitzer 1990; Dabrowska and Pisula 2010; Hayes and Watson 2013). Parents of children with ASD also report lower quality of life (Pozo and Sarria 2014; Vasilopoulou and Nisbet 2016). Parent stress and quality of life have been related not only to the impact of the child's ASD symptoms, but also to additional life stressors, coping, and internal and external resources that also explain significant variances in outcomes (Benson 2006; Boyd 2002; Bristol 1987; Ekas et al. 2010; Giallo et al. 2013; Hastings and Brown 2002; Kuhn and Carter 2006; McStay et al. 2014; McCubbin and Patterson 1983; Paynter et al. 2013; Pozo and Sarria 2014; Stuart and McGrew 2009). More recently, self-compassion as a novel and potentially modifiable predictor has emerged in contemporary quantitative research. A recent meta-analysis found that interventions can increase self-reported self-compassion with moderate to large effects (Kirby et al. 2017), and have recently been integrated in a parenting intervention for mothers of infants (Mitchell et al. 2018). Further, survey-based studies have shown self-compassion has been related to parental adaptation, parental stress and quality of life both in parents of children with ASD and typically developing (Bohadana et al. 2019; Neff and Faso 2015; Torbet et al. 2019; Wong et al. 2016). However, little, if any research has explored the lived experience of mothers of children with

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ASD and their experiences with self-compassion using a qualitative approach. Therefore, the aim of the current study is to investigate mothers' experiences in parenting children with ASD along with their understanding and experiences with self-compassion.

The majority of researchers examining self-compassion in parents of children with ASD have used Neff's (2003) Self-compassion scale and conceptualisation of self-compassion. Neff (2003) conceptualises self-compassion as comprising of three interrelated components: self-kindness versus self-judgement, common humanity versus isolation, and mindfulness versus over-identification. According to Neff, self-kindness refers to being understanding, caring, and gentle towards oneself during times of distress, or perceived failures, as opposed to being self-attacking and berating towards oneself. Common humanity refers to the ability to understand that everyone makes mistakes and experiences adversity during their lifetime. Lastly, mindfulness refers to the non-judgemental acceptance and awareness of negative thoughts and feelings (Neff 2003). According to Neff (2003), rather than ruminating or dwelling on negative emotions, mindfulness allows individuals to be accepting, and have an increased awareness of their emotions.

Self-compassion has been found to be a significant predictor of outcomes for parents of children with ASD (Bohadana et al. 2019; Neff and Faso 2015; Torbet et al. 2019; Wong et al. 2016). Originally, Neff and Faso (2015) investigated self-compassion in 51 parents (40 mothers and 11 fathers) of children aged 4–12 years with an ASD diagnosis. They found that self-compassion was a moderator between ASD symptom severity (i.e., symptom frequency) of the child and parental stress. Specifically, parents high in self-compassion showed a low correlation between their child's symptom severity and their stress. Other outcomes associated with self-compassion included greater life satisfaction, increased sense of hope, increased goal re-engagement, reduced levels of depression and relationship dysfunction, and better perceptions of the child's difficulties. Consistent with these findings, Wong et al. (2016) found self-compassion to be a protective factor against the affiliate stigma (i.e., the internalisation of external criticisms) experienced by 180 Chinese parents of children with ASD. Using a quantitative survey design, they found self-compassion moderated the association between affiliate stigma and psychological distress, in that for parents with high-self compassion, the association between affiliate stigma and psychological distress was lower. Similarly, Torbet et al. (2019), examined self-compassion as a protective factor against affiliate stigma in 257 Australian parents of children with ASD aged 18 years or younger using a quantitative approach and Neff's (2003) full self-compassion scale. They found affiliate stigma was no longer a significant predictor of parental subjective well-being once self-compassion was added to the model. Thus,

self-compassion may be a protective factor against the challenges of adapting to child ASD symptoms (Neff and Faso 2015), affiliate stigma for parental well-being (Torbet et al. 2019) and psychological distress (Wong et al. 2016) in both Western and non-Western populations.

More recently, Bohadana et al. (2019) examined self-compassion in the context of the Double ABCX model in 139 parents of children with ASD. The Double ABCX model proposes there are several factors that may contribute to parental outcomes. These parental outcomes include the child's level of symptom (e.g., core ASD symptomatology or associated features such as challenging behaviour), pile-up of life stressors that may be unrelated to the child (e.g., financial stress), the perception of the situation, parental self-efficacy, external resources (e.g., social support), and coping strategies (Bristol 1987; McCubbin and Patterson 1983). Consistent with other Double ABCX model research (Benson 2006; Boyd 2002; Bristol 1987; Giallo et al. 2013; Hastings and Brown 2002; Kuhn and Carter 2006; McStay et al. 2014; Paynter et al. 2013; Pozo and Sarria 2014; Stuart and McGrew 2009), this study found that factors such as parental perceptions, parental self-efficacy, social support, and pile up of demands significantly predicted both stress and quality of life in separate regressions. Additionally, they found that self-compassion added a unique significant amount of the variance in parental stress and quality of life once these established predictors of outcomes were entered in the model. Specifically, the negative dimension of self-compassion (i.e., isolation, over-identification, and self-judgement) was related to greater parental stress. On the other hand, the positive dimension of self-compassion (i.e., common humanity, mindfulness, and self-kindness) was related to greater quality of life.

Most of the research on self-compassion in parents of children with ASD to date has been of quantitative design using self-reported measures (Bohadana et al. 2019; Neff and Faso 2015; Torbet et al. 2019; Wong et al. 2016). Across these studies as indicated earlier, the main measure used has been Neff's (2003) self-compassion scale, but it has been analysed and scored in varying ways. For example, some studies used the full-scale score (Neff and Faso 2015; Torbet et al. 2019; Wong et al. 2016), whereas others investigated the negative and positive dimensions separately (Bohadana et al. 2019). Research relying on self-report measures alone may exclude real world (or the lived) experiences and challenges that parents face.

While there is limited qualitative research into self-compassion, with none to the authors' knowledge on parents of children with ASD, there is limited qualitative research into self-compassion in other populations. For example, a study by Pauley and McPherson (2010) investigated self-compassion in individuals with a diagnosis of either depression or anxiety using semi-structured interviews ($N = 10$).

Participants identified benefits to being self-compassionate such as helping to manage their depression and anxiety and as a reminder to be kinder to themselves in challenging times. They however, also identified challenges to being self-compassionate (due to their condition, due to being difficult and effortful, and due to social isolation/disconnection). This early study provides insight into some of the lived experience of the challenges, aids, and benefits of self-compassion in individuals with depression and anxiety.

There is also some qualitative research on stress and coping more generally in parents of children with ASD with a focus on mothers (Gray 2006; Kuhaneck et al. 2010; Luong et al. 2009), and the experiences of stress in fathers specifically (Paynter et al. 2018), the impact of parenting a child with ASD in families living in rural Canada (Hoogsteen and Woodgate 2013) and the perceived benefits of raising a child with ASD (e.g., Markoulakis et al. 2012). Furthermore, research on eight fathers by Paynter et al. (2018) highlighted that fathers of children with ASD face challenges that include struggling to take time for themselves, as well as enduring physical and mental health difficulties as a result of their stress. The current body of research has provided useful insight into the some of the perceived benefits, experiences, coping strategies, and challenges faced by parents of children with ASD, but has not yet explored self-compassion as a possible protective factor and potential avenue for interventions and supports into the future. To date, there has been no research on the lived experience of self-compassion and any potential for self-compassion to be a helpful mechanism for reducing stress in parents of children with ASD. Parents of children with ASD experience severe difficulties and our understanding of the factors that influence such difficulties, particularly modifiable skills such as self-compassion (Barnard and Curry 2011; Neff and Germer 2013) is important. Research that explores the lived experiences of parents is crucial in understanding parents' unique experiences, which will then help inform interventions specifically targeted at reducing parental stress and improving parent outcomes. Research suggests parents of children with ASD have a unique experience of stress compared to other parent groups (Hayes and Watson 2013), and so it is important to examine their experience in greater depth.

Summary and Rationale for the Current Study

Previous research mainly focused on gaining a quantitative understanding of the adaptation of parents (typically mothers) of children with ASD, been a-theoretical, or did not include self-compassion. Additionally, limited studies have explored the lived experience of parents with children with ASD. The potential benefits of self-compassion in parents of children with ASD (Bohadana et al. 2019; Neff and Faso 2015; Torbet et al. 2019; Wong et al. 2016), and in other

populations has been highlighted (Neff, 2003; Neff et al. 2007; Neff and McGehee 2010; Pauley and McPherson 2010; Robinson et al. 2018). However, qualitative research on self-compassion in parents of children with ASD is essential to understand the richness of experiences and insights into real-life challenges in the context of parenting a child with ASD. Therefore, given the preponderance of mothers as the typical care givers for children with ASD, the current study explored the lived experience and the perceived stress in mothers of children with ASD through semi-structured interviews conducted over the phone. Each mother was contacted individually and was asked the same questions as per the interview protocol adapted from Pauley and McPherson's (2010) study (see supplemental materials for a copy). This research also explored the extent to which these mothers were able to be self-compassionate in their daily encounters with the challenges of parenting a child with ASD. We were particularly interested in understanding the perceived stress and the extent to which mothers could make use of being self-compassionate in managing daily stressors.

Research Questions

1. What are mothers' lived experience of stress?
2. How do mothers view and experience self-compassion in their day-to-day lives in the context of parenting a child with ASD?

Method

Design

A qualitative research design was employed using semi-structured interviews, with ethical approval by the University Ethics Committee [2018/37].

Participants

A convenience sample of 19 mothers was recruited from a previous study into factors that influence parents' adaptation (Bohadana et al. 2019). Recruitment ceased once 19 interviews had been conducted consistent with qualitative guidelines for reaching saturation (Polkinghorne 1989). Nineteen mothers with at least one child aged between 6 and 12 years with an ASD diagnosis from a paediatrician which was verified by the research team using the Social Communications Questionnaire (Rutter et al. 2003), participated in the research. The cutoff used for verification was 11, as recommended by previous research (Allen et al. 2007; Eaves et al. 2006; Norris and Lecavalier 2010) and mean scores for the SCQ were 28.07, SD = 2.93 Range = 21–38.

The mean age of the mothers was 39.19 years ($SD = 3.56$, $Range = 31.00–50.00$ years). The average age of their child was 8.50 years ($SD = 1.96$ years), and average age at diagnosis was 5.34 years ($SD = 2.57$). Thirteen of the children had an additional diagnosis (e.g., Attention Deficit and Hyperactivity Disorder, Generalised Anxiety Disorder, Global Developmental Delay, etc.), and half of the children were male. Two mothers reported their partner to have an ASD diagnosis. Eighteen of the 19 mothers were born in Australia and all mothers reported English to be their first language. Seventeen mothers had a tertiary level of education or above and two-thirds were married.

Materials and Procedure

Semi-structured interviews were completed via telephone and were audio-recorded for transcription with participant consent. The interview protocol (available from first author) included questions exploring mothers' perceived stress, and their understanding of self-compassion. The interview questions were adapted from Pauley and McPherson (2010). Questions were adapted to be specifically targeted at parents of children with ASD, rather than individuals with depression and anxiety. For example, questions around depression and anxiety were changed to better focus on stress. All questions were piloted and tested with a 45-year-old, married mother of a child with ASD, and feedback regarding wording was incorporated into the final interview protocol (see supplementary materials for a copy). Key areas included mothers being asked whether it was possible to be self-compassionate, and whether being self-compassionate helped them during times of stress. In addition, mothers in the current study were informed of the main findings from the first phase of the research (Blinded for review) and were invited to respond to questions such as "We found X in our study, how does that fit with your experience?". Mothers were also invited to respond to questions about their experience of stress, their understanding of self-compassion, and the extent to which the different components of self-compassion are manifested for them during times of stress. Interview durations ranged from 30 min to an hour, depending on the parent. On average, the duration of interviews was 44.5 min ($SD = 7.30$). Interviews were transcribed verbatim by the first author and correspondence checks were completed with mothers (to verify transcriptions) with no changes made by any participant.

Analysis

Thematic analysis was conducted using the six steps of thematic analysis (Braun and Clarke 2006). First, to get familiarised with the data, verbal responses were transcribed, and the breadth and depth of content was identified. During this

phase, the first author collected notes for coding. In phase two, initial codes were identified to organise the raw data into meaningful groups that later formed the basis of recurring themes (Tuckett 2005). The third phase involved organising the identified codes into broader themes or sub-themes. Any data that did not fit into a theme was retained under a separate theme for the fourth phase.

In the fourth phase, the themes that had been identified thus far were refined. At this stage, themes that had little data to support them, themes that could be collapsed with other themes, or themes that needed to be broken down into separate themes were identified. The internal homogeneity and external heterogeneity were examined at this stage. In that, we made sure that the data within themes were related in a meaningful way, whereas data from separate themes were distinguishably different. To check this, all collated data extracts within each theme were read and formed a coherent pattern. If a clear pattern did not form within each theme, then that theme was revised. If a clear pattern was apparent, then the next step was to consider the validity of each theme in relation to the data set, and whether the themes reflected the meanings of the whole data set.

Once a thematic map of the data had been established, the next phase involved defining and naming themes. The definition and name of each theme stemmed from the essence of what each theme was about, and what aspect of the data each theme encompassed. For each theme, a detailed analysis was conducted to identify the 'story' that each theme told, and how it fit with the overall, broader narrative that the data told in relation to the research questions (e.g., What is the lived experience of mothers of children with ASD, and what is their experience of self-compassion during times of parenting related stress?). Where needed, sub-themes were formed to give a better structure to large or complex themes.

The last phase involved the production of the report. This was achieved by providing appropriate evidence of the identified themes and including direct quotes that capture the relevant points derived from the themes. The write up involved providing an argument and a narrative, as well as evaluating the data in relation to the research questions, as opposed to a mere description of the findings.

Inter-rater Reliability Check

Once codes and themes were generated, a second, independent coder with clinical experience coded and assigned codes for 50% of the interview transcriptions. Of the 85 codes generated in these interviews, both coders agreed on 79 codes and their associated themes, yielding a Cronbach's Kappa coefficient of .93. For assigning of codes to individual statements, a Cronbach's Kappa coefficient of .91 was yielded. The second and third authors independently sorted codes into themes and discussed consensus until consistency

emerged. Any disagreements regarding coding and theme names were resolved by discussion among the authors. *For example, one theme derived by the first author was “non-judgemental validation” and we have included that under the “Emotional Validation” sub-theme upon agreement. Other examples of themes included “Better perspective taking” or “Seeing things from different perspectives” and so those were deemed to be a better fit for the “Helpful thinking and perspective” sub-theme (Perceived benefits of self-compassion overarching theme).*

Findings

Four general themes emerged from parent interviews: *Parent stress: causes and impact, Perceived benefits of self-compassion, Aids to self-compassion, and Barriers to self-compassion.* Each theme is comprised of sub themes, see Table 1. Pseudonyms are used throughout this section.

Theme 1: Parent Stress Causes and Impact

Six sub-themes were identified in terms of parent stress causes and impact: ASD features and diagnosis, feeling different and alone, difficulties coping, impact on system, impact on cognition and thought, and impact on the self (see Fig. 1).

ASD Features and Diagnosis

Mothers indicated a lack of knowledge, the impact of the diagnosis on themselves, and child’s wellbeing as being important influences on their own stress. They explained

that their stress mainly relates to the specific features and symptoms of their child’s ASD and the impact of these, such as their inability to go places due to noise or lights that may trigger their child. For example, *“Dealing with a child who has ASD and the behaviours they have can sometimes be very challenging to stay in control, it’s so stressful”* (Sarah, a 33-year-old married mother of an 8-year-old boy). Mothers also reported they believe that their experience of stress is almost dependent on the child’s emotional state. Several mothers reported that watching their child struggle emotionally is the most difficult part of being a parent of a child with ASD. For instance, Lucy, a 42-year-old mother of a 9-year-old shared: *“There are many sides to her emotionally, and it’s the hardest thing to watch her struggle, so as long as she’s happy then I’m happy”*. Some mothers also indicated that the stress they experience is related to their lack of knowledge about the disorder, and that they noticed increased stress specifically at the time of receiving the formal diagnosis. For example, Angela, a 39-year-old mother of an 8-year-old stated: *“My son just recently received his diagnosis and I’m almost left with ok, what does that mean, and it’s really difficult”*. Several mothers mentioned that at diagnosis, they were uncertain of how to best care for their child and realised that they immediately felt increased stress. Moreover, mothers reported the uncertainty about their, and their child’s future also served to heighten their stress. This idea was captured by Sarah (33): *“I just don’t know what is going to happen, my children are 6, and 8 and as an ASD parent you’ve got to actually think 5 years ahead each time which is overwhelming, you just don’t know what is going to happen in the future”*. They specifically discussed their worries around their child managing in the world when they are no longer around.

Table 1 Themes and Sub-themes derived from parents’ experiences

Themes	Sub-themes
1. Parent stress causes and impact (see Fig. 1)	ASD features and diagnosis Feeling different Difficulties coping Impact on system Impact on cognition and thought Impact on self
2. Perceived benefits of self-compassion (see Fig. 2)	Positive coping Helpful thinking and perspective Emotional validation
3. Aids to self-compassion (see Fig. 3)	Social support and understanding Internal resources Knowledge
4. Barriers to self-compassion (see Fig. 4)	Mindfulness difficulties Competing priorities

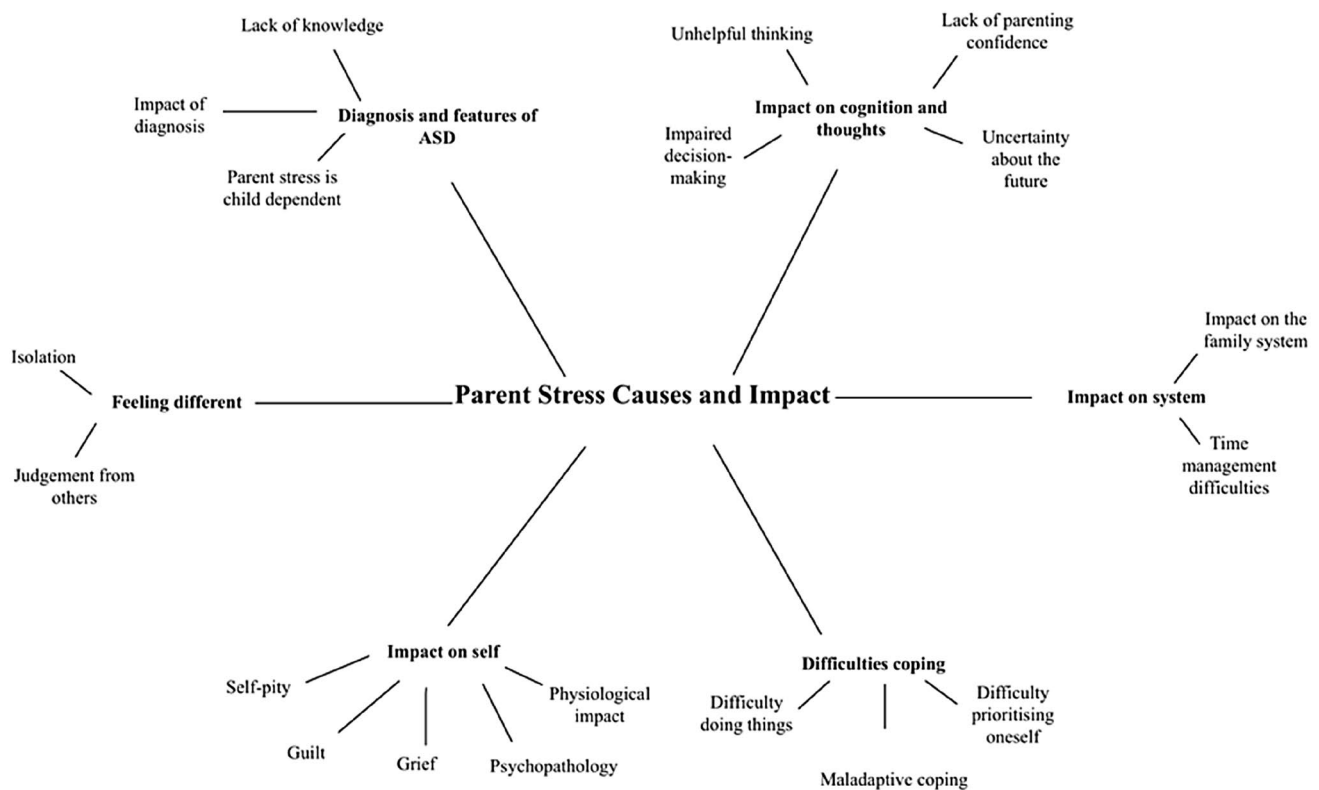


Fig. 1 Sub-themes and their associated codes for theme 1

Feeling Different and Alone

Mothers also mentioned that feeling different contributed to their feelings of stress, and their perception was that other mothers did not understand what it is like to parent a child with ASD. Mothers reported feeling different stemmed mainly from feeling judged by society and other parents, as well as feeling isolated and alone. For example, Mary, a 36-year old divorced single mother of a home-schooled 10-year-old boy shared: *"I think there needs to be a change in society and a lot more acceptance as well. I feel like as a parent you're continually fighting social norms and outside perceptions and people don't understand and that makes it really hard..."*.

Difficulties Coping

Mothers reported that they struggle to cope in times of stress. This was manifested in their inability to do things that they enjoy (e.g., see friends or engage in sporting activities) or communicate with others. They reported that it is more difficult to go out in public due to feeling "down" and being unable to cope properly. Almost all mothers mentioned they currently experience difficulty prioritising themselves in times of stress, and that they struggle to put themselves first

as a parent of a child with ASD, whom requires their full attention, for example, *"when you're stressed in those situations it's hard to find the time to then go and do something for yourself"* (Sue, 46 years, full-time carer of 8-year-old).

Impact on System

Most mothers indicated that the impact of stress was manifested across their family and work life. For example, most mothers reported the stress is impacting their family system. For example, mothers reported being less patient and getting upset with the children more frequently. They reported their stress can impact the way the whole family copes, for example: *"if I'm not coping then the rest of my family is not coping and it keeps going in a circle. It prevents me from practicing what I preach on the importance of forgiving yourself and that it's ok to make mistakes, which is what I want my kids to know"* (Sue, 46-year-old). They also reported that stress impacted on their ability to manage their time, and find a balance between work, parenting, and taking time for themselves, for example *"... it was difficult to find a sort of parenting, home, work sort of balance. I had, work wise, a lot on my plate, parent wise, and unable to keep up the household in the routine that it needed to."* (Anna, 34-year-old married mother of a 10-year-old).

Impact on Cognition and Thought

Some mothers reported that stress impacts their cognition and thought and noticed that they experienced unhelpful thinking. They indicated that stress decreases their confidence as a parent and their approach to parenting. Several mothers stated that stress eroded their ability to think clearly, interfered with their ability to make decisions, and diminished their ability to see a clear future. Jane, a 35-year old separated mother of a 6-year old girl shared: *"umm sometimes those big comments come up in your head, like, why me, I hate life, you know, you get these really unhelpful thinking styles come up sometimes so that I think it changes how you feel as a person"*.

Impact on Self

All mothers highlighted that the stress directly impacted their physiological adaptation. Several reported increased muscle tension, and "tightening of the heart". In addition, psychological impacts of stress, including experiences of depression, anxiety, loss of pleasure and motivation to do anything were reported by many mothers in this study. Similarly, almost all mothers reported that their experience of stress was associated with feelings of parenting guilt, grief that their child would not be able to participate or achieve certain things in life, and their sense of feeling sorry for themselves. This is captured by experiences shared by Alana, a 31-year old married mother of a 7-year-old boy: *"The stress can then quite quickly turn into anxiety and depression and then you don't seem to want to do anything at all, whether it's good or bad and then if you sink into that hole its more difficult to pull yourself out and get moving again"*.

Theme 2: Perceived Benefits of Self-compassion

Mothers were invited to share their experiences and understanding of self-compassion. Most mothers understood

self-compassion as having the ability to be kind, caring, forgiving towards themselves, as well as to be mindful. Key sub-themes identified in perceived benefits were engaging in positive coping (e.g., time management, self-care), helpful thinking, and emotional validation (see Fig. 2).

Positive Coping

Mothers indicated that they believed being self-compassionate had several benefits for coping with parenting a child with ASD. This included an increased ability to engage in self-care and do things for themselves. They also indicated that they believed being self-compassionate improved their responses to others, resulting in more positive relationships with friends and family. Some mothers reported that being self-compassionate helped with having better time management and allowed them to put themselves first in their busy schedule without feeling guilty. These mothers also highlighted that being self-compassionate was helpful in the context of their own parenting and parenting confidence. Specifically, they stated being self-compassionate enabled them to be more self-reflective and open to the child's experience. These benefits are captured by Lauren, a 41-year-old separated mother of an 11-year old who highlighted that: *"I think when we're more compassionate about ourselves it opens our reflective ability more... you can be a better parent because then I can be more open and engaged and be more open for her emotionally"*.

Helpful Thinking and Perspective

Mothers also reported that being more self-compassionate helped improve their ability to think about the situation from multiple perspectives, which also seemed to increase their ability to be empathic. Additionally, most mothers stated that being self-compassionate promoted their sense of self-kindness and self-forgiveness, which allowed them to move forward. Hannah, a 49-year old divorced mother of a 9-year-old boy shared: *"Umm I think my compassion towards myself*

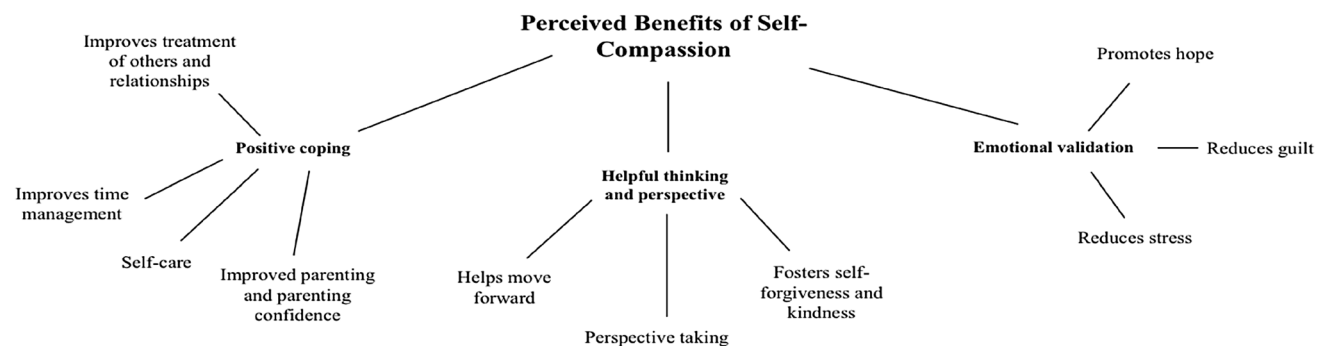


Fig. 2 Sub-themes and their associated codes for theme 2

and towards Morgan has enabled us to move forward and keep developing. I think if I didn't have compassion towards myself, I'd probably hand him over to someone else. It helps with forgiving yourself when you're having these moments".

Emotional Validation

Mothers reported that they believed being self-compassionate led to better emotional coping. They mentioned that having a sense that others share similar experiences and have gotten through the difficulties promotes hope for the future. They stated that being self-compassionate reduced their guilt by allowing themselves to make mistakes in their parenting. Mothers also identified the positive impact of self-compassion on alleviating their stress. Julie, a 37-year old married mother of a 6-year old boy stated: "I think the benefit would be more of a system in that I guess being more compassionate during those times of high stress load would probably ultimately dampen the stress, if that makes sense, like I think the stress would be less intense".

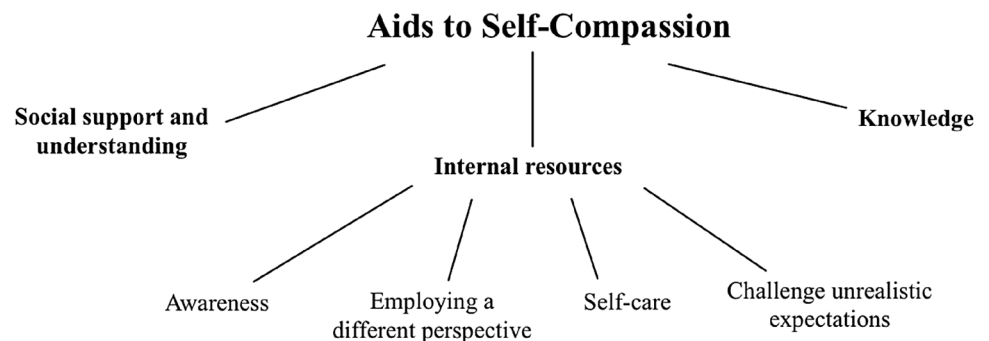
Theme 3: Aids to Self-compassion

Mothers discussed several factors that could aid their ability to engage in self-compassion, falling under three sub-themes: social support and understanding, internal resource, and knowledge, see Fig. 3.

Social Support and Understanding

Mothers spoke about what would help them have more self-compassion. More than half of the mothers suggested having more social support and help from other people would help them to be more self-compassionate. They mentioned that receiving validation and understanding from family, friends, parents and professionals is helpful in having more compassion towards themselves. They reported that understanding the child's diagnosis "was sort of like almost a relief and a bit of compassion from people who came and gave the diagnosis helped be more self-compassionate" (Mary, 33 years old).

Fig. 3 Sub-themes and their associated codes for theme 3



Internal Resources

Mothers identified the need for resources to improve self-compassion. These include cognitive capabilities such as having more awareness during times that require them to be more self-compassionate. They stated it involves the ability to "take time and being able to recognise the need for self-kindness" (Hannah, 49 years old). They also discussed the notion that being in the moment and focusing on the positives over the negatives helps increase their self-compassion. Moreover, mothers mentioned that taking the time to self-care is helpful. They also reported that having the internal ability to challenge unrealistic expectations from themselves, other parents, and society helps shift the focus to what is important and increases their ability to be self-compassionate without feeling guilty. This was echoed by Maria, a 36-year-old full-time carer to an 8-year-old, who shared: "its important to know that you're not a failure, and that making mistakes is a part of life and that makes it a lot easier to forgive yourself and move on without sinking in the guilt".

Knowledge

Mothers discussed the need for knowledge and education about ASD and the realities of parenting a child with ASD to be able to accept the situation and be more self-compassionate. Hannah suggested: "Education, a lot of education around realities of autism and the realities of managing autism in isolation. I think, for me its education... It's mainly education, that's what would help people to learn to be more self-compassionate".

Theme 4: Barriers to Self-compassion

Mothers identified that their ability to be self-compassionate is impacted by several barriers. The barriers mothers identified were mindfulness difficulties and competing priorities, see Fig. 4.

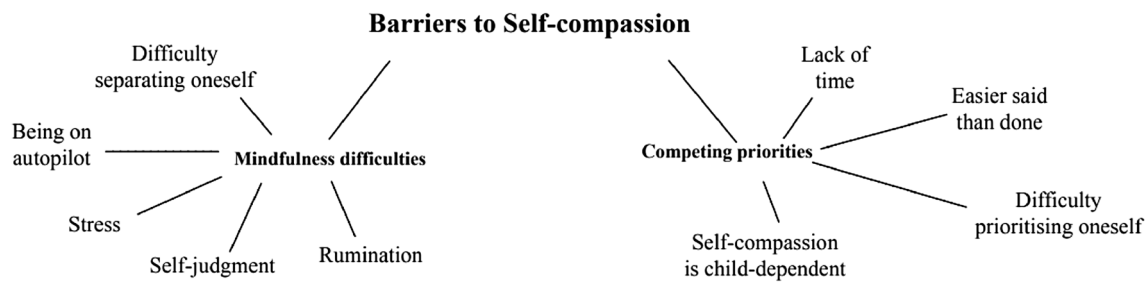


Fig. 4 Sub-themes and their associated codes for theme 4

Mindfulness Difficulties

Mothers reported that their difficulty to be mindful affects their ability to be self-compassionate. The inability to be mindful stems from their difficulty to separate themselves from the stressful situation and feeling as if they are functioning on autopilot. They also stated that feeling stressed can hinder their ability to be self-compassionate, as they often tend to judge themselves and ruminate. For example, Venessa, a 32-year old mother of a 7-year-old shared: *“If something goes wrong, you’re always harder on yourself, like I should have done this, I should have done that. I shouldn’t have gotten angry, I shouldn’t have and shouldn’t haven’t, there’s so many I shouldn’t have’s and you’re constantly overthinking things”*.

Competing Priorities

Mothers indicated that competing priorities make it difficult to be self-compassionate. Specifically, they highlighted that being self-compassionate is easier said than done, and that lack of time and difficulty prioritising themselves make it particularly difficult. They reported that they usually have too much on their plate, and it is difficult to schedule self-care into their routine. Shelly, a 34-year-old mother of a 10-year-old described: *“I tend to put myself last on the list of things that need to be done. I guess I don’t have time for myself and everything I need gets put to the side”*. They mentioned they feel as though they can only take time out for themselves when others have been taken care of. Additionally, mothers suggested that their ability to be kind and compassionate towards themselves is dependent on their child’s happiness and state. Another common description reported by mothers is the *“need for permission from others to just take that time out”* (Erin, a 31-year-old married mother of a 7-year old boy).

Discussion

Nineteen mothers shared their personal experiences of stress and self-compassion in the context of parenting a child with ASD. Consistent with the literature (Gray 2006; Hoogsteen

and Woodgate 2013; Kuhaneck et al. 2010; Luong et al. 2009; Paynter et al. 2018), mothers revealed that the parenting children with ASD is a complex experience and the stress that they experiences is influenced by multiple factors such as the child’s diagnosis, difficulties coping and feeling different and impacts several areas of their life and functioning. Mothers’ understanding of self-compassion was aligned with conceptualisations by Neff (2003) as they expressed it as encompassing self-forgiveness, self-understanding, and non-judgemental awareness. While mothers in this study acknowledged the potential benefits of self-compassion in managing their parenting such as the helpful thinking, emotional validation, and positive coping, they also highlighted the potential barriers that may hinder their ability to successfully engage in or experience self-compassion. Nevertheless, mothers also identified the potential aids support, internal resources and knowledge that could assist them in being more self-compassionate.

Maternal Experiences of Stress

The mothers highlighted several factors that contribute to their stress including lack of understanding from others, the suffering of their child, and their own difficulty in prioritisation themselves. Consistent with findings from quantitative research (Bohadana et al. 2019; Bristol 1987; Giallo et al. 2013; Hastings et al. 2005a, b; McStay et al. 2014; Manning et al. 2011; Paynter et al. 2018), these mothers reported stress stemming from not understanding their child and their child’s experiences and their own inability to cope in a positive way. They identified that the lack of understanding of their child’s emotional suffering and their inability to resolve their child’s problems, was stressful, and they highlighted that they were happier and less stressed when their child was going well compared to times when they perceived that their child was suffering. These findings are consistent with previous research (Benson 2010; Ekas et al. 2010; Hastings et al. 2005a, b, Paynter et al. 2018). Furthermore, the mothers in this study acknowledged that their difficulty to prioritise themselves did not allow them to address such internal concerns (e.g., stress) as it arises, and this struggle with being

kind to themselves during times of stress, tended to exacerbate their stress.

Mothers also acknowledged that their experience of stress impacted the way they interact with their child, as well as their relationships with other people. They reported that stress inhibited their ability to develop positive relationships with their child and other individuals negatively impacting the family. In that, mothers highlighted their concern around the importance and the great difficulty of modelling self-compassionate behaviour during stressful times. While they recognised the importance of practicing what they preach in the hope that their child will develop appropriate emotional and behavioural reactions in response to stress, they reported that stress can make it difficult to model appropriate behaviour and identified this as a discrepancy between their values and behaviour, which exacerbates their distress further. These findings highlight the bi-directional and reciprocal relationship between parental stress and child-related challenges as noted recently by Yorke et al. (2018). Our findings provide further evidence of this relationship and a possible explanation of how the impact that parental stress-related behaviours and maladaptive coping may be modelled to the child and therefore exacerbate challenging behaviour.

Mothers mentioned stress can impact them internally and cognitively, in that the stress leads to unhelpful thinking patterns, impaired decision making, reduced parenting self-efficacy, and feeling hopeless about the future. This is consistent with previous research which indicates there is a relationship between parent stress and parental self-efficacy (Giallo et al. 2013; Hastings and Brown 2002; Kuhn and Carter 2006). This suggests that parental stress can impact the way they feel about their parenting and their parenting confidence, which in turn impacts the way they parent their child. The internalisation of the difficulties they face in their parenting may then lead to added stress and functional impairment.

Mothers were well aware that their own stress could contribute to additional problems, such as anxiety, depression and physical concerns such as heart palpitations and increased heart rate. They also reported stress impacting their ability to manage their time effectively and balance their home, work, and individual responsibilities. Therefore, for these mothers, stress appeared to lead directly to mental and physical health concerns, and to challenges in time management that resulted in their taking less care of their own physical and mental health. This is consistent with findings from Paynter et al. (2018) who likewise found fathers reported putting their own health last. Such findings suggest the impact of stress on mothers is particularly concerning, as it does not only impact their own adaptation, but it impacts their cognitions, physical and mental health, relationships, and the way they function in several contexts. Their difficulty coping in times of stress suggests they may not possess or utilise effective coping strategies, which is consistent

with previous research (e.g., Gray 2006). This may be due to their difficulty prioritising themselves and the guilt they experience if they do so, as has been found in other qualitative studies of mothers of children with ASD (Paynter et al. 2018). As such, this highlights the importance of investigating positive stress management strategies and coping, as well as addressing cognitions that may form barriers to taking care of themselves.

Maternal Experiences with Self-compassion

Expanding on previous quantitative research (Bohadana et al. 2019; Neff and Faso 2015; Torbet et al. 2019; Wong et al. 2016), which identified a link between self-compassion and parental outcomes (e.g., parental stress, quality of life, psychological distress, and/or well-being), we explored three main themes in mothers' experiences of self-compassion. First, they discussed the benefits of self-compassion and according to the mothers the benefits associated with self-compassion may mitigate some of the causes and negative impact of stress. Mothers provided novel, yet practical insight into how self-compassion can lead to more positive coping strategies in the face of stress, such as being able to better manage their time, improving their confidence in their parenting due to being less self-critical, and being able to set a positive example for their child. Importantly, the idea that self-compassion may mitigate the guilt mothers feel when prioritising themselves in times of stress was acknowledged. Mothers also highlighted that self-compassion improves their thinking and perspective in that it enables them to focus on the positives, be able to forgive themselves when they make mistakes, and move forward. This indicates that self-compassion may negate the self-doubt and low confidence mothers reported experiencing in times of stress. Furthermore, mothers reported that self-compassion also helps foster better emotional coping and hope about the future, which in turn reduces their stress. Mothers' experiences of the benefits of self-compassion are parallel to their accounts of stress-related factors.

Moreover, validation and permission from others to be kind to themselves was identified as key in fostering self-compassion. Mothers reported social support and understanding from family, friends, other parents, and professionals is extremely important in alleviating stress by allowing them to be more self-compassionate, and this is consistent with previous research, (Benson 2006; Bohadana et al. 2019; Boyd 2002; Manning et al. 2011; Stuart and McGrew 2009). Furthermore, this aligns well with Neff's (2003) definition of self-compassion as including common humanity and feeling their challenges are shared by others. Consistent with this, mothers had reflected on feeling different to others as a barrier to self-compassion, which highlighted that having the ability to challenge unrealistic expectations from themselves

or society reduces their self-criticism and enhances their self-compassion and ability to engage in self-care. Such findings highlight the importance of support from others, as well as mothers' own capabilities and resources in experiencing self-compassion.

Mothers acknowledged that having a better understanding of ASD themselves, and greater understanding of ASD within the broader society is key in fostering self-compassion. They believed that greater understanding of the problems associated with ASD would enable them to be more self-forgiving, and less self-critical especially when mistakes can be attributed to a misunderstanding of the symptoms and characteristics associated with ASD, as opposed to their specific parenting. This is also consistent with Paynter et al. (2018) who also found that the challenges related to the ASD symptoms despite the physical visibility of a disability (e.g., social understanding difficulties) were often also misunderstood by society. Such findings capture the common humanity component of self-compassion as highlighted by the desire of mothers to feel as if their experiences and their child's needs are shared and understood despite the lack of physical markers.

Mothers also reported that being self-compassionate is particularly difficult due to competing priorities. They acknowledged that self-compassion requires prioritising themselves, which can often be easier said than done especially when their focus is on the child and other responsibilities, and they are 'time-poor'. Mothers indicated the difficulty they experience practising being mindful. In particular, they acknowledged the sense of often being on autopilot and finding it difficult to distance themselves from their child's problems, and view situations more objectively. This in turn, made it difficult not to be aware that self-care is required and led to being more self-critical or to feel guilty. The theme of guilt has also been raised in Paynter et al.'s (2018) research, where fathers reported feeling guilty for having time for themselves.

Mothers in this study identified the reciprocal relationship between stress and self-compassion. They recognised that while the ability to be self-compassionate appears to reduce the impact of stress, and to enable mothers to cope more positively, the barriers to being self-compassionate appear to correspond with a more negative experience of stress. For example, mothers reported it is difficult to prioritise themselves in times of stress yet knowing that engaging in self-compassion assists with time management. This highlights the importance of acknowledging both the benefits and barriers to using self-compassion in designing parent interventions. Specifically, increasing self-compassion in mothers of children with ASD may mitigate the negative factors related to parent reported stress. It is crucial to include strategies to address parent reported barriers to self-compassion interventions. For example, strategies to help mothers

better manage their time and increase their awareness will be helpful in facilitating the development or enhancement of self-compassion, and in turn reduce stress. Since mothers reported a need for validation from others, parent programs should highlight and teach the importance of being compassion with others as well as with self. This is consistent with Wong et al. (2016) whom identified that self-compassion may serve as a protective factor against the stigma mothers may experience from others. Thus, interventions may also need to include other parents, friends or family members, in order to emphasise the importance of compassion from others in facilitating mothers' own self-compassion.

Limitations and Future Research

The current study provides initial exploration of the experience of stress and self-compassion in Australian mothers of children with ASD complementing previous quantitative research in this area. To our knowledge this is the first qualitative exploration of self-compassion in this group, building on emerging quantitative research (Bohadana et al. 2019; Neff and Faso 2015; Torbet et al. 2019; Wong et al. 2016). Nevertheless, there are several limitations that need to be addressed. First, given that accounts were derived from mothers, there is a need for the voices of fathers to be acknowledged as highlighted by previous researchers (Paynter et al. 2018), as well as the voices of other individuals within the family unit. Therefore, future research should aim to investigate the unique experiences of stress and self-compassion in other family members including fathers, grand-parents and siblings. Second, the current study was conducted in Australia, and the meaning and experience of self-compassion may differ in other populations or cultures. Conducting culturally sensitive research that incorporates the values and experiences of the target population will be important to inform understanding and interventions that are socially and culturally valid. Third, the collection of data through one to one interview by an interviewer (who was not a parent/parent of child with ASD) may have impacted on the information shared by participants. Finally, the interviewer's stance in favour of self-compassion may have influenced elicitation and interpretation of parent responses. However, the standardisation of the semi-structured interview guide and having the interviews all conducted by the same researcher, as well as the use of correspondence checks, blind coding, and multiple-rater coding, provides some rigour to this process. Nevertheless, understanding contextual factors that may impact on the experience reported by mothers and parents is important, and other methods such as focus groups with parents in a similar position may elicit differing perspectives to triangulate findings from previous quantitative and current qualitative research.

Implications and Conclusions

The current study is the first to consider the lived experience of both stress and self-compassion in mothers of children with ASD as shared in their own words through individual interviews. Mothers shared important insights into causes of stress for them and the meaning of self-compassion in their life. They provided practical examples of how self-compassion can assist in their daily living in the context of raising a child with ASD. Mothers highlighted the benefits of self-compassion particularly around mitigating some of the negative causes and outcomes associated with parental stress. The factors that help mothers enhance self-compassion also emerged in themes. There is potential to translate interventions used with other groups (e.g., online self-compassion interventions) to parents of children with ASD, given the feasibility demonstrated in other parent groups (e.g., Mitchell et al. 2018), and the significance of self-compassion in both previous quantitative research (Bohadana et al. 2019) and the current study. Thus, given the modifiable nature of self-compassion (Kirby et al. 2017), it is important to consider parents' lived experience of stress and self-compassion in the future to help inform the development of interventions that consider specific parent experiences. The experiences of mothers in the current study also highlight the factors that hinder the ability of mothers to be self-compassionate. The barriers identified including mindfulness difficulties and competing priorities should be considered when designing self-compassion-based interventions. Our findings shed light on the importance of developing self-compassion-based interventions to enhance self-compassion, while accounting for the specific barriers to self-compassion such as the lack of time, and mindfulness difficulties. Such interventions will in turn also address the factors associated with parent stress. Given the clinically high stress in parents of children with ASD and the impact it has on the family system, there is a need for more parent-based interventions that can effectively reduce parental stress and increase positive parent and child outcomes. Self-compassion may provide a modifiable factor to facilitate better adaptation for parents and their children with ASD.

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Compliance with Ethical Standards

Conflict of interest There was no conflict of interest in conducting this research.

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