



## Death concerns and psychological well-being in mothers of children with autism spectrum disorder



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### ABSTRACT

**Purpose:** Utilizing a terror management theory perspective, the present research examined whether having a child with autism spectrum disorder (ASD) is associated with underlying cognitions and explicit worries about death, and their roles in psychological well-being.

**Method:** 147 mothers of children with ASD ( $n = 74$ ) and typically developing children ( $n = 73$ ) completed a fear of death scale, as well as measures of death-thought accessibility, positive and negative affect, depression, and anxiety.

**Results:** Following previous research, mothers of children with ASD reported worse psychological health. Additionally, they evidenced greater death-thought accessibility compared to mothers of typically developing children, but did not differ in explicit worries about mortality. Greater death-thought accessibility, in turn, mediated the influence of ASD diagnosis on negative affect, depression, and anxiety.

**Conclusion:** The current study offers an initial understanding of the association between mortality concerns and psychological health for mothers of children with ASD. Further, it underscores the importance of health care providers' efforts to attend to, and educate parents about, their thoughts of mortality, even if the parent does not acknowledge such concerns.

**What this paper adds:** The present study examined the impact of both implicit and explicit worries about death in parents of children with Autism Spectrum Disorder (ASD). Specifically, we were able to demonstrate that increased death-thought accessibility among mothers of children with ASD was associated with worse psychological health. While it is possible for parents of children with ASD to report conscious worries about death, there were no observed differences on this measure. As far as we know, this work is the first to empirically examine the prevalence of mortality-related concerns in this population and the subsequent effects of death-thought accessibility on psychological health. This is an important avenue of research as parents of children with ASD may experience greater worries about leaving their children upon death with no one to care for them, or to leave their children in the care of individuals who may not understand their son or daughter's unique needs. Additionally, the current findings highlight the importance of addressing mortality-related concerns, even when they may not be explicitly recognized, among parents of children with ASD. Given the effectiveness of parent education programs for children with ASD, a primary avenue for intervention may be education. Training care providers in ways to better discuss thoughts of death may help to alleviate stress and foster greater psychological well-being.

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Autism spectrum disorder (ASD) is estimated to affect more than two million individuals in the United States and tens of millions worldwide (Centers for Disease Control, 2015). It is a neurodevelopmental disorder that is characterized, in varying degrees, by difficulties in verbal and non-verbal communication, social interaction, and repetitive behaviors. Given that many children with ASD experience a lack of functional independence and/or engage in maladaptive behaviors (e.g., aggression, self-harm; [Devon et al., 2014](#)), the severity of the disorder is often associated with caregiving burden and lower quality of life. For example, several studies have shown that mothers of children with ASD report higher feelings of anxiety and depression, experience more relationship problems, have diminished physical health, and express greater worries about the future (see e.g., [Karst & Van Hecke, 2012](#) for a review). Although research has established a connection between children with ASD and the well-being of their mothers ([Abbeduto et al., 2004](#); [Blacher & McIntyre, 2006](#); [Eisenhower, Baker, & Blacher, 2005](#)), no work has examined the prevalence of mortality-related concerns in this population.

According to terror management theory ([Greenberg, Solomon, & Pyszczynski, 1986](#)), people are motivated to mitigate the potential for anxiety inherent in the awareness of death so that this potential does not bloom in debilitating terror. Individuals may do so by identifying with culturally derived values and beliefs (i.e., cultural worldviews) that make life seem more meaningful, significant, and enduring (see e.g., [Pyszczynski, Greenberg, Koole, & Solomon, 2010](#) for a review). Unfortunately, parents of children with ASD may experience a breakdown in cultural worldviews associated with being a competent and effective caregiver (e.g., parenting self-efficacy; [Giallo, Wood, Jellett, & Porter, 2013](#)). In families of children with ASD, research has shown that parents feel less confident in taking care of their of their children ([Losh, Childress, Lam, & Piven, 2008](#)); they feel frustrated and doubtful about their parenting abilities ([Sofronoff & Farbotko, 2002](#)); and they often question their treatment decisions given the abundance of interventions available ([Mackintosh, Goin-Kochel, & Myers, 2012](#)). Encountering such worldview disruptions may not only undermine parents' perceptions of their competence and meaning in life ([Giallo et al., 2013](#)), but they may make caregivers more vulnerable to increased worries about death.

Additionally, terror management theory suggests that individuals buffer themselves against the threat of mortality by (a) maintaining a sense of self-worth and (b) turning toward relationships with close others for comfort and support. Research demonstrates that parents with children with ASD experience problems in both of these domains. For instance, mothers of children with ASD report higher levels of distress and lower levels of self-esteem in comparison to mothers of typically developing children ([Hassall, Rose, & McDonald, 2005](#); [Tomanik, Harris, & Hawkins, 2004](#)) and mothers of children with Down Syndrome, Fragile X, and cerebral palsy ([Abbeduto et al., 2004](#); [Blacher & McIntyre, 2006](#); [Eisenhower et al., 2005](#); [Kasari & Sigman, 1997](#)). Lower well-being in mothers of children with ASD is associated with less than optimal parenting, failure to engage with their offspring, and impeded child development ([Brinker, Seifer, & Sameroff, 1994](#); [Llewellyn, McConnell, Thompson, & Whybrow, 2005](#); [O'Connor, 2002](#)). Relationship problems are also commonly observed among parents of children with ASD. For example, several studies have found that parents of children with ASD have significantly higher separation and divorce rates ([Hartley, Mihaila, Otolor-Fadner, & Bussanich, 2010](#)); they experience greater problems in raising their children ([Stuart & McGrew, 2009](#)); and they report more arguments with their loved ones ([Kelly, Garnett, Attwood, & Peterson, 2008](#)). Researchers identify ASD-related parental distress, caregiving burden, and financial demands as particularly damaging to close relationships ([Karst & Van Hecke, 2012](#)).

It appears that being the parent of a child with ASD is associated with problems in domains that provide protection against mortality awareness (i.e., cultural worldviews, self-esteem, and close relationships). The purpose of the present research was to examine the connection between thoughts of death and psychological well-being in mothers of children with ASD and a comparison group of mothers of typically developing children. Mothers were of particular interest given their primary caregiver status ([Hartley, Mihaila, Otolor-Fadner, & Bussanich, 2014](#)) and the results of previous work demonstrating that mothers of children with ASD suffer from worse health compared to fathers ([Davis & Carter, 2008](#); [Herring et al., 2006](#); [Sharpley, Bitsika, & Efremidis, 1997](#); [Tehee, Honana, & Hevey, 2009](#)). The current study was designed with three goals in mind. First, following previous research ([Abbeduto et al., 2004](#); [Blacher & McIntyre, 2006](#); [Eisenhower et al., 2005](#)), we examined the associative link between having a child with ASD and the well-being of the mothers. It was hypothesized that mothers of children with ASD would report greater negative affect, anxiety, and depression in comparison to mothers of typically developing children.

Second, the present research explored the effects of parental condition (ASD vs. typically developing) on explicit worries about death and a more subtle measure of the extent to which mothers have active thoughts of mortality (i.e., death-thought accessibility). Although there is the potential that explicit concerns about death are associated with lower psychological well-being among mothers of children with ASD, research suggests that unacknowledged thoughts of mortality may also affect quality of life ([Cox, Reid-Arndt, Arndt, & Moser, 2012](#); [Vess, Routledge, Landau, & Arndt, 2009](#)). Indeed, previous research suggests that thoughts of death are often suppressed to remove such cognitions from focal awareness ([Schimmel, Hayes, Williams, & Jahrig, 2007](#)). As such, we examined with particular interest the accessibility of death-related thought, hypothesizing that mothers of children with ASD would evidence greater death-thought accessibility compared to mothers of typically developing children, but were more tentative as to whether such differences would emerge for explicit worries about death.

Finally, the current study examined the mediating effects of accessible death cognition in understanding the link between having a child with ASD and the psychological well-being of mothers. It was hypothesized that heightened death-thought accessibility would be associated with poorer psychological health among mothers of children with ASD (compared to mothers of typically developing children), but that explicit worries about death may not manifest similar results. The present research thus provides the first empirical study of how parenting a child with ASD can be associated with explicit and

implicit (i.e., death-thought accessibility) thoughts of mortality, and their respective association with emotional and psychological health.

## 1. Method

### 1.1. Participants

A total of 147 mothers served as participants in the study ( $M_{\text{age}} = 36.82$ ), with a majority of parents being Caucasian (82%), married (67%), and having an annual household income \$40,000 or more (65%). 74 of the mothers had children with ASD ( $M_{\text{age}} = 39.15$ ), whereas 73 women ( $M_{\text{age}} = 34.34$ ) were mothers of typically developing children. Demographic information for the two parent conditions is presented in Table 1.

Results revealed significant differences among parenting conditions on the demographic variables (see Table 1 for inferential statistics). First, there was a significant effect of age, with mothers of children with ASD being older than the mothers of typically developing children. Additionally, there was a significant association between parenting condition and ethnicity, marital status, and household income. An examination of the standardized residuals for each analysis, with z-scores greater than  $\pm 1.96$  indicating statistical significance at  $p = .05$  (Field, 2013), found that there were fewer African-Americans than expected in the ASD condition compared to more African-Americans than expected in the control condition. Further, for relationship status, more individuals were single in the control condition (vs. ASD condition); and, for household income, mothers of children with ASD were higher than expected on earning \$100,000+ compared to mothers of typically developing children.

### 1.2. Procedure

Mothers of children with ASD were paid \$10 for their participation and were recruited from flyers posted around the local community, internet announcements, and message boards (Facebook) in the United States and Canada. Parents needed to have a child between the ages of 4 and 12 who had received a diagnosis of ASD from either an educational or health professional (see e.g., Weiss, Cappadocia, Tint, & Pepler, in press for similar parental self-report procedures). Diagnosing clinicians varied, with 39% of the mothers indicating that their child was diagnosed by a multidisciplinary team (e.g., pediatrician and other health professional), 19% by a psychologist, 3% by a psychiatrist, and 39% by a medical doctor. 99 mothers, who emailed the researchers expressing interest in the study, were sent a Qualtrics link (an online survey software program) to complete questionnaires on their computer. Participants were sent a reminder email if they did not

**Table 1**  
Parent characteristics as a function of child type (ASD vs. typically developing).

Variable	ASD		Typically developing	
	Mean (SD)		Mean (SD)	
Age	39.26 (5.53)		34.34 (6.29)	
Age range (years)	28–55		21–53	
	<i>n</i>	%	<i>n</i>	%
Ethnicity				
Caucasian	67	90.5	54	74.0
African-American	1	1.4	12	16.4
Hispanic	4	5.4	4	5.5
Asian	1	1.4	3	4.1
Other	1	1.4	0	0
Marital status				
Single	4	5.4	25	34.2
Married	62	83.8	36	49.3
Separated/Divorced	7	9.5	12	16.4
Widowed	1	1.4	0	0
Income				
Less than \$14,999	2	2.7	2	2.7
\$15,000–\$24,999	9	12.2	16	22
\$25,000–\$39,999	7	9.5	16	21.9
\$40,000–\$74,999	22	29.7	24	32.9
\$75,000–\$99,999	12	16.2	6	8.2
Over \$100,000	22	29.7	9	12.3
Statistics for age differences as a function of condition (ASD vs. Typically developing)				
	<i>t</i>	<i>df</i>	<i>p</i>	Cohen's <i>d</i>
	5.03	145	$\leq .001$	.84
Statistics for demographic variables as a function of condition (ASD vs. Typically developing)				
Variable	$\chi^2$	<i>df</i>	<i>N</i>	<i>p</i>
Ethnicity	12.70	4	147	.005
Marital status	24.42	3	147	$\leq .001$
Household income	13.01	5	147	.02

take part in the survey within a few days (a total of 3 reminder emails were sent 7–10 days apart across the study period (approximately 6 months)). 74 mothers completed the online survey. No demographic information was collected for individuals who did not complete the survey.

Mothers of typically developing children were recruited from the United States and Canada using Amazon's MTurk ([www.mturk.com](http://www.mturk.com)) where they were paid \$5 for their participation. MTurk is an online forum where researchers can post survey links and pay individuals for their participation (Buhmester, Kwang, & Gosling, 2011; Casler, Bickel, & Hackett, 2013). It has become an increasingly popular tool for social science research because data have been found to match the reliability of other methods (e.g., face-to-face testing, Facebook), and many psychology experiments have been successfully replicated using MTurk samples (Azzam & Jacobson, 2013; Berinsky, Huber, & Lenz, 2012; Casler et al., 2013; Horton, Rand, & Zeckhauser, 2011; Mason & Suri, 2012). In the current study, a prescreen survey was administered to mothers to ensure that their child was between the ages of 4 and 12 without an ASD diagnosis (Yes/No: "Has your child been diagnosed with a developmental or learning disability?"; "Has your child been diagnosed with an autism spectrum disorder?"). Of the 129 women who completed the pre-survey, only 73 of them met the inclusion criteria for this experiment. There was no significant difference in demographic characteristics (i.e., age, marital status, race, socioeconomic status) between individuals who were included and not included in the study. Data collection on MTurk lasted for approximately 14 days.

The study was conducted online and participants in both conditions were asked to complete materials on an individual basis. Everyone was informed that they were taking part in an experiment on the "social and emotional functioning of parents." Informed consent was obtained following institutional guidelines (i.e., participants' check-marked that they agreed to participate in the survey and provided their name as a form of consent), and all mothers were told that they could stop participation at any time and still receive payment. All questionnaires were presented in English at or below a 6th grade reading level (Radloff, 1977; Spielberger, Gorsuch, Lushene, & Jacobs, 1983), and everyone was thoroughly debriefed (in writing) upon the study's completion. The survey took approximately 30 min to complete. The content and order of the questionnaire is described below.

### 1.3. Measures

#### 1.3.1. Death cognition

Participants completed a word fragment task to measure the accessibility of death-related thoughts (Hayes, Schimel, Arndt, & Faucher, 2010; Schimel et al., 2007). This widely used method presents word fragments that can be completed with different words, one of which is relevant to the construct of interest (Gilbert & Hixon, 1991; Tulving, Schachter, & Strack, 1982). Asked to complete the fragments with the first word that comes to mind, the more fragments a participant completes with (in this case) death-related words, the more death is inferred to be cognitively accessible and influencing perception. In the present study, participants were presented with 30 word fragments (e.g., TAB \_\_ (table)), 6 of which could be completed with a neutral or death-related word (DE \_\_ (dead or deed), GRA \_\_ (grave or grape), BUR \_\_ D (buried or burned), CO \_\_ SE (corpse or course), SK \_\_ \_ (skull or skill), COFF \_\_ (coffin or coffee)). Variants of this measure have been used extensively in previous terror management research (see Hayes et al., 2010 for a review), including among parent populations (Yaakobi, Mikulincer, & Shaver, 2014). Following prior work (Arndt, Greenberg, Solomon, Pyszczynski, & Simon, 1997; Cox et al., 2008; Greenberg, Pyszczynski, Solomon, Simon, & Breus, 1994), death accessibility scores were calculated by summing together the number of death-related words with which participants completed the fragments. The possible range was from 0 (none of the fragments were completed with death-related words) to 6 (all of the fragments were completed with death-related words).

#### 1.3.2. Explicit death concern

To measure explicit worries about death, participants completed a 15-item fear of death scale (Conte, Weiner, & Pluchik, 1982). Example items included, "Do you worry about dying?" and "Are you worried about not knowing what to expect after death?" Each statement was answered on a True/False scale, and all affirmative responses were summed together for a total score (parents of individuals with ASD, Kuder-Richardson = .79; parents of individuals without disabilities, Kuder-Richardson = .89).

#### 1.3.3. Mood

The 20-item Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988) was included to assess individuals' current mood on a 5-point scale (1 = very slightly or not at all; 5 = extremely). Scores were calculated by taking the sum of the 10 items for each subscale (positive affect: parents of individuals with ASD  $\alpha = .90$ , parents of individuals without disabilities  $\alpha = .89$ ; negative affect: parents of individuals with ASD  $\alpha = .87$ , parents of individuals without disabilities  $\alpha = .91$ ).

#### 1.3.4. Depression

The 20-item Center for Epidemiologic Studies Depression inventory (CES-D; Devins et al., 1988) measured symptoms of depression over the past week using a 4-point scale (1 = rarely or none of the time; 4 = most or all of the time). Example items included, "I felt depressed" and "I felt lonely." All positive items were reverse coded so that a higher score indicated greater feelings of depression (parents of individuals with ASD  $\alpha = .91$ , parents of individuals without disabilities  $\alpha = .93$ ).

### 1.3.5. State anxiety

Everyone completed the 20-item state measure of the State-Trait Anxiety Inventory (STAI; Spielberger et al., 1983). Statements included, “I feel tense” and “I am worried.” Responses were made on a 4-point scale (1 = not at all; 4 = very much so). All positively worded items were reversed scored and summed together to create a total measure of anxiety (parents of individuals with ASD  $\alpha = .61$ , parents of individuals without disabilities  $\alpha = .94$ ).

All of the well-being measures (i.e., PANAS, state depression and state anxiety) were selected because they have been frequently used in parenting populations (Belsky, Crnic, & Woodworth, 1995; Jaser & Grey, 2010; Paulson, Dauber, & Leiferman, 2006), including mothers of children with ASD (Benson, 2012; Ekas & Whitman, 2011; Estes et al., 2013).

### 1.4. Data analysis plan

Sample size was based, in part, on effect sizes within the terror management literature. A meta-analysis conducted by Burke, Martens, and Faucher (2010) found that terror management studies have moderate effect sizes ( $r = .35$ ). This suggests that, in a between-subjects design, at the .05 alpha level with power at .80 (Faul, Erdfelder, Lang, & Buchner, 2007), at least 30 participants were needed in each condition. Qualtrics, the online software program used to collect participants' responses, recorded everyone's data into one SPSS (Statistical Packages for the Social Science) file to download. Two researchers (independent of each other) coded the word fragment task by determining whether the six words of interest (e.g., DE \_ \_) were completed with death-related (i.e., dead) or neutral (e.g., deed) completions. There was 100% agreement between the two coders. Death accessibility scores were computed by summing the number of death words created by each participant (Hayes et al., 2010; Schimel et al., 2007). All analyses were conducted using SPSS Version 22. First, frequency tests were performed to assess for missing data. Whereas there was no missing data for mothers of children with ASD, one mother in the typically developing condition did not have scores for the state anxiety measure. She was included in all of the analyses aside from this assessment. Second, preliminary results found that the data met the assumptions of independence, normality, homogeneity of variance, and linearity (i.e., mediation); therefore, parametric tests were used for all analyses. Third, given the significant difference between conditions on the demographic variables, all analyses were performed with age, race, marital status, and household income entered as covariates. Two-tailed analysis of covariance (ANCOVA) tests were performed with alpha set at .05 to determine statistical significance. (None of the covariates were significant ( $ps \geq .09$ ) and our results remained significant when the demographic variables were included in the analyses.) Follow-up tests were conducted using the Bonferroni adjustment to reduce the likelihood of committing a Type I error. Fourth, mediation analyses were conducted using the SPSS macro “Indirect” (Preacher & Hayes, 2004). This allowed us to use multiple regression procedures in addition to including our demographic variables as covariates in each analysis (Hayes, 2009). Negative affect, depression, and anxiety scores were regressed separately onto parenting condition (dummy coded: ASD = 0, typically developing = 1), with death cognition scores entered as the mediator. For each mediational model, 10,000 bootstrap resamples were performed and the 95% confidence interval was used to determine statistical significance. Finally, Cohen's  $d$  was used as a measure of effect size for the ANCOVA results (.20 = small effect, .50 = medium effect, and .80 = large effect; Cohen, 1988, 1992) whereas  $R^2$  was utilized for the mediational findings (.02 = small effect, .13 = medium effect, and .26 = large effect; Cohen, 1988).

## 2. Results

**Hypothesis 1:** Mothers of children with ASD should report lower levels of psychological well-being in comparison to mothers of typically developing children. The results revealed a significant effect of parenting condition on negative affect, depression, and anxiety scores, with mothers of ASD children reporting worse health compared to mothers of typically developing children. There was no significant difference among parenting conditions on positive affect scores. See Table 2 for inferential and descriptive statistics.

**Hypothesis 2:** Mothers of children with ASD should experience greater death-thought accessibility compared to mothers of typically developing children. Results revealed no significant difference among conditions on explicit concerns about death as assessed by the fear of death scale (Conte et al., 1982). There was, however, a significant association between parenting condition and death word completions, with mothers of children with ASD completing more fragments with death-related words than those with typically developing children. Inferential and descriptive statistics are reported in Table 2.

**Hypothesis 3:** Heightened death-thought accessibility should be associated with lower well-being for mothers of ASD children but not mothers of typically developing children. Preacher and Hayes' (2004) bootstrapping procedure examined whether death-thought accessibility mediated the association between parenting condition and well-being. As previously reported (Hypothesis 1), and meeting the first criterion for mediation, there was a significant association between parenting condition and well-being scores ( $c$  path; see Table 3 for inferential statistics for mediation). Further, the second step of mediation demonstrated a link between the predictor variable (parent condition) and the mediator (death cognition;  $a$  path; Hypothesis 2). A third set of analyses examined the association between death cognition and well-being while controlling for

**Table 2**

Well-being and death scores as a function of parenting condition (ASD vs. typically developing) while controlling for demographic variables (ANCOVA).

Variable	ASD	Typically developing		
	Mean (SD)	Mean (SD)		
Positive affect	29.92 (8.23)	28.97 (8.36)		
Negative affect	16.64 (6.39)	12.89 (5.56)		
Depression	16.39 (10.19)	12.78 (10.28)		
Anxiety	43.05 (6.12)	36.34 (12.10)		
Death cognition	1.27 (.82)	.99 (.75)		
Explicit death concern	5.91 (3.34)	6.84 (4.57)		
Variable	F	df	p	Cohen's d
Positive affect	.01	1, 141	.92	.05
Negative affect	15.45	1, 141	≤.001	.97
Depression	8.85	1, 141	.003	.84
Anxiety	20.98	1, 140	≤.001	1.00
Death cognition	4.95	4.95	.03	.60
Explicit death concern	10.85	1, 141	.41	.13

parenting condition (*b* path). Greater death-thought accessibility was associated with increased feelings of negative affect, depression, and anxiety. The final step examined the connection between parenting condition and well-being when death accessibility scores were entered as a mediator (*c'* path). 10,000 bootstrap resamples were performed and the 95% confidence interval obtained for the indirect effect did not contain zero (negative affect:  $-1.71, -.10$ ; depression:  $-3.13, -.25$ ; anxiety:  $-2.20, -.15$ ). When death-thought accessibility scores were entered into the model as a covariate, the effect of parenting condition on depression, negative affect, and anxiety remained significant, suggesting partial mediation. Overall, these results suggest that the path between parenting condition and well-being is indirect: greater death-thought accessibility accounts for a portion of lower well-being experienced by mothers who have children with ASD.

### 3. Discussion

Parenting a child with ASD engenders a multitude of worries, some explicitly acknowledged and some not, with secondary effects on perceived quality of life. The current study examined whether thoughts of mortality were related to the psychological health of mothers of children with ASD. As expected, and consistent with previous research (Benson & Karlof, 2009; Bitsika & Sharpley, 2004; Bromley, Hare, Davidson, & Emerson, 2004; Sharpley et al., 1997), mothers of children with ASD reported greater negative affect, depression, and anxiety compared to mothers of typically developing children. Further, although there was no significant difference among conditions on explicit worries about death, the results showed that mothers of children with ASD reported higher levels of death-thought accessibility compared to those with typically developing children. This measure provides unique insights previously unrecognized in the literatures on terror management theory, ASD, caregiving, and well-being. That is, the path between ASD diagnosis and parental well-being was indirect: greater death-thought accessibility was associated with detriments in health among those with children with ASD.

**Table 3**

The direct and indirect effect of parenting condition (dummy coded: ASD = 0, typically developing = 1) on well-being through death-thought accessibility while controlling for demographic variables.

Parent condition predicting well-being ( <i>c</i> path)					
Variable	<i>b</i> (SE)	<i>B</i>	<i>t</i>	<i>p</i>	<i>R</i> <sup>2</sup>
Negative affect	-4.32 (1.10)	-.34	3.93	≤.001	.10
Depression	-5.49 (1.84)	-.27	2.97	.004	.06
Anxiety	-7.95 (1.74)	-.40	4.58	≤.001	.13
Parent condition predicting death cognition ( <i>a</i> path)					
Variable	<i>b</i> (SE)	<i>B</i>	<i>t</i>	<i>p</i>	<i>R</i> <sup>2</sup>
Death cognition	-.31 (.14)	-.20	2.22	.03	.03
Death cognition predicting well-being when controlling for parent condition ( <i>b</i> path)					
Variable	<i>b</i> (SE)	<i>B</i>	<i>t</i>	<i>p</i>	<i>R</i> <sup>2</sup>
Negative affect	2.06 (.64)	.26	3.20	.002	.06
Depression	4.07 (1.06)	.31	3.82	≤.001	.09
Anxiety	3.00 (1.02)	.24	2.93	.004	.05
Parent condition predicting well-being when controlling for death cognition (mediation, <i>c'</i> path)					
Variable	<i>b</i> (SE)	<i>B</i>	<i>t</i>	<i>p</i>	<i>R</i> <sup>2</sup>
Negative affect	-3.68 (1.08)	-.30	3.40	.001	.07
Depression	-4.23 (1.79)	-.21	2.36	.02	.03
Anxiety	-7.08 (1.72)	-.35	4.12	≤.001	.10

The present results have important implications for research on terror management theory. Specifically, several terror management theorists have argued that parent-child relationships are important at reducing anxieties associated with mortality awareness (Cox et al., 2008; Fritsche et al., 2007; Wisman & Goldenberg, 2005; Yaakobi et al., 2014). For instance, parenthood can serve as a literal form of immortality by passing one's genes onto future generations (Lifton, 1979). Additionally, having children can increase people's feelings of self-worth and validate their belief systems as parents transmit their cultural worldviews from one generation to the next (Wisman & Goldenberg, 2005). Given that the three critical components to the individual anxiety-buffering system are cultural worldviews, self-esteem, and close personal relationships, the present results suggest that parents with children with ASD may experience problems in one or more of these domains, leading to a higher accessibility of death-related thought. If this is the case, then we suspect that parents of children with ASD may respond differently to reminders of death compared to parents of typically developing children (Yaakobi et al., 2014).

The current research also highlights the importance of studying the impact of both implicit and explicit worries about death in parents of children with ASD. Specifically, we were able to demonstrate that increased death-thought accessibility among mothers of children with ASD was associated with worse psychological health. While it is possible for parents of children with ASD to report conscious worries about death, there were no observed differences on this measure. Several studies have shown that it is often the accessibility of death-related thoughts rather than the direct emotional experience of anxiety that drive attitudes and behaviors aimed at managing mortality-related concerns (Pyszczynski et al., 2010). While future research is needed to further explore the roles of these different expressions of death-related cognition, the present study points to the promise of such inquiry.

The present results also add to the literature on ASD and parental well-being. Specifically, research consistently finds that parents of children with ASD report decreased parental self-efficacy, experience increased stress, and have greater problems with physical and psychological health compared to parents of typically developing children, as well as children with other developmental disabilities (Abbeduto et al., 2004; Blacher & McIntyre, 2006; Eisenhower et al., 2005; Giallo et al., 2013; Hassall et al., 2005; Kasari & Sigman, 1997; Losh et al., 2008; Tomanik et al., 2004). Moreover, having a child with ASD has been shown to decrease quality of life within families and lead to increased marital conflict and sibling relationship problems (Hartley et al., 2010; Kelly et al., 2008). As far as we know, the present study is the first to empirically examine the prevalence of mortality-related concerns in this population and the subsequent effects of death-thought accessibility on psychological health. This is an important avenue of research as parents of children with ASD may experience greater worries about leaving their children upon death with no one to care for them, or to leave their children in the care of individuals who may not understand their son or daughter's unique needs. Also, parents may spend more time considering the aging of their physical bodies, their own mortality, and the emotional and psychological toll that their death will have on their children with ASD (De Wolfe, 2014). Although the present study provides a first step in understanding the interplay among ASD, parental well-being, and mortality-related concerns, more research is needed on the prevalence of explicit and implicit worries about death, the effectiveness of the terror management anxiety buffering system, and the extent to which detriments in well-being extend to domains beyond psychological health (e.g., physical, social).

### 3.1. Policy implications

Additionally, the current findings highlight the importance of addressing mortality-related concerns, even when they may not be explicitly recognized, among parents of children with ASD. Given the effectiveness of parent education programs for children with ASD (e.g., Karst & Van Hecke, 2012), a primary avenue for intervention may be education. Training care providers in ways to better discuss thoughts of death may help to alleviate stress and foster a more protective support system. Social support is not only important in coping with a child's ASD diagnosis, but previous research has found that close relationships help to buffer against thoughts of mortality (Mikulincer, Florian, & Hirschberger, 2003). Additionally, when offering therapy to parents of children with ASD, clinicians may want to assess their patients' perceptions of meaning and value in life given that they have both been previously identified to buffer death cognition (Pyszczynski et al., 2010). Critically, the current research underscores the importance of health care providers' efforts to attend to, and attempt to counsel and educate parents about, their thoughts of mortality, even if the parent does not acknowledge such concerns.

### 3.2. Limitations

Although we found that death-thought accessibility mediates the association between having a child with ASD and the psychological well-being of mothers, there are some limitations to this work. First, although the study materials have been previously used in parent populations (Yaakobi et al., 2014), we never pilot-tested them in parents of children with ASD. Future research should attempt to replicate the current findings among different parent populations with a higher response rate among participants. Second, because the study was cross-sectional in nature, it remains unclear whether differences observed are due to having a child with ASD or extraneous characteristics. If raising a child with ASD is associated with greater death cognition and lower well-being, one question is whether these effects occur longitudinally and/or become exaggerated over time as parents move into old age and closer to death. This is an important avenue for future study as some parents may plan better for their child's future than others, a variable that was not assessed in the current study. Third, given that we found significant differences among parenting conditions on demographic characteristics (i.e., age, race, marital

status, and socioeconomic status), more research should be done matching individuals on these variables to reduce any confounding problems. Further, since we used a sample of convenience, there may have been a self-selection bias between individuals who volunteered to participate in the present experiment and those who did not. Future studies should assess whether the current results can be replicated among different populations, including minority and low-income families.

Additionally, in common with most studies among caregivers, the participants in the current study were exclusively mothers. One direction for future research is to see if our findings extend to fathers, even though several studies have found that mothers of children with ASD often experience greater distress and lower well-being compared to their male counterparts (Davis & Carter, 2008; Herring et al., 2006; Little, 2002; Sharpley et al., 1997; Tehee et al., 2009). Moreover, although research has found that parents with children with ASD experience compromised health in comparison to parents of both typically developing children and children with developmental disabilities (Abbeduto et al., 2004; Blacher & McIntyre, 2006; Eisenhower et al., 2005; Giallo et al., 2013; Hassall et al., 2005; Kasari & Sigman, 1997; Losh et al., 2008; Tomanik et al., 2004), the present research lacked a comparison group of mothers with children with other disabilities. This limits the ability to make conclusions about relative levels of death-thought accessibility and well-being across different parent populations.

Future research also needs to examine the associative link between death concerns and the anxiety-buffering system in parents with children with ASD. Specifically, although the present findings demonstrate that mothers of children with ASD experience a greater accessibility of mortality-related thought leading to lower well-being, they do not provide any evidence that such individuals have compromised anxiety-buffering system mechanisms. To demonstrate this, studies need to show that increasing thoughts of close relationships, validating parents' cultural worldviews (e.g., parental self-efficacy), and/or boosting self-esteem provides protection against mortality concerns, reduces the accessibility of death-related thought, and makes less necessary use of other defenses. In support, preliminary evidence among college students has found that activating thoughts of parenthood reduced death-thought accessibility (Yaakobi et al., 2014) and general defensiveness (Fritsche et al., 2007) following mortality salience manipulations.

The current study also failed to examine individual difference factors that might moderate the association between heightened mortality awareness and health detriments in parents of children with ASD. For instance, the intellectual disability of the child (i.e., having a higher functioning child vs. a lower functioning child) might play an important role in the well-being of parents. Additionally, it has been found that siblings of children with ASD are at a greater risk of developing ASD than siblings of typically developing children (Rutter, 2005). They may also exhibit language and social impairments, as well as emotional and psychological difficulties (e.g., anxiety, depression; Bolton, Pickles, Murphy, & Rutter, 1998; Smalley, 1997). Given the impact of having a child with ASD on the well-being of parents, it seems important to take into consideration the number of offspring and their symptomology as a potential moderating variables. Finally, parents with children with ASD have been shown to use a variety of different coping strategies (e.g., positive reframing, emotion regulation; Pottie & Ingram, 2008); they may try to make meaning out of their parenting experience (e.g., religiosity; Tarakeshwar & Pargament, 2001); and/or they may vary in their feelings of parental self-efficacy (e.g., Karst & Van Hecke, 2012). Given that we were unable to account for all of the explained variance in our results, an examination of these and other individual differences (e.g., demographic and family characteristics) may shed light on the accessibility of death-related thought and the effectiveness of the anxiety-buffering system in parents with children with ASD.

#### 4. Conclusion

In sum, ASD is a disorder with far-reaching consequences for those who are affected, along with their families. Parents of children with ASD are at greater risk of experiencing stress, mental and physical health problems, and report lower competency and parental self-efficacy (Giallo et al., 2013; Hassall et al., 2005; Losh et al., 2008; Tomanik et al., 2004). In addition to significant financial strain and increased time pressures (Karst & Van Hecke, 2012), parents of children with ASD experience higher rates of divorce and lower overall family well-being (Hartley et al., 2010; Kelly et al., 2008). Given the diagnosis of ASD is on the rise in the United States and elsewhere (Centers for Disease Control, 2015), the importance of efforts to help parents with children with ASD is apparent, and we believe that the integration of social and developmental perspectives has significant potential to contribute to these efforts. That is, the current results offer an initial understanding of the associative link between mortality concerns and psychological health for mothers of children with ASD. Additionally, it suggests that tapping into thoughts of death that are not explicitly reported may help future research to understand, and ultimately mitigate, some of the psychological impacts of having a child with ASD.

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