

THE ROLE OF DEATH CONCERNS  
IN THE WELL-BEING OF  
PARENTS WITH  
AUTISTIC CHILDREN

by

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ABSTRACT

Autism spectrum disorder (ASD) is a developmental disorder characterized by difficulties in social interaction, communication, and repetitive behaviors that affects 1 in every 88 school-age children (Blumberg et al., 2013). Parenting a child with ASD has proven to be a difficult task, changing the lives and well-being of families. The current research examined the buffering effects of raising an ASD child on the anxieties related to death (terror management theory; Greenberg, Solomon, & Arndt, 2008). To do this, parents of ASD children and parents of typically developing children were asked to complete an online survey reporting thoughts of death, fear of dying alone, and meaning in life. Unexpectedly, parents did not differ on thoughts of death; however, results revealed that parents of ASD children reported decreased fear of dying a lonely death, which in turn, increased feelings of meaning in life. The implications of these results of ASD children parents' well-being will be further discussed.

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## INTRODUCTION

Autism Spectrum Disorder (ASD) is a developmental disorder that is characterized by a range of issues including impaired verbal and nonverbal skills, problems with social interactions, difficulties with emotional reciprocity, repetitive behaviors, restricted interests, and emotional distress from environmental changes (American Psychiatric Association, 2013). The diagnosis of ASD is growing in numbers, currently believed to affect 1 in 88 children (Centers for Disease Control and Prevention 2008). Parenting a child with ASD has proven to be a difficult task, changing the lives and well-being of families (Davis & Carter 2008; Faso, Neal-Beevers, & Carlson 2012; Harper, Dyches, Harper, Roper, & South 2013; Karst & Van Hecke 2012). One fear for many parents is what might happen to their ASD children after they die. The purpose of the present study was to examine if parents of children with autism report greater concerns about death compared to parents of typically developing children, and how heightened mortality concerns might affect the psychological well-being of parents of children with ASD.

### **Parenting a Child with Autism Spectrum Disorder (ASD)**

Parenting, in general, can create excess stress and anxiety, but parenting a child with ASD can be exceptionally stressful. Research has shown that parents raising children with ASD have elevated levels of stress in both mothers and fathers (e.g., Davis & Carter, 2008), with an even higher increase among mothers (e.g., Kuusikko-Gauffin et al., 2012). Additionally, several studies demonstrate that parenting a child with ASD is more difficult and stressful on parents than raising a child with another developmental disorder such as Down Syndrome, ADD/ADHD, Cerebral Palsy, and other intellectual disabilities (Brobst, Clopton, & Hedrick, 2009; Dabrowska & Pisula, 2010; Hayes & Watson, 2013; Lee, Harrington, Louie, & Newschaffer, 2008; Meadan, Stoner, & Angell, 2010; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Olsson & Hwang 2001). Specifically, research has found that tantrums

and behaviors associated with excessive self-stimulation associated with ASD increase stress and depression for parents (Stuart & McGrew, 2009). This research has been supported cross culturally, and has been shown to be the result of ASD as opposed to other factors related to parenting (e.g., individual daily stressors, maternal mental health, & social interaction issues; Hastings, 2008; Krulik et al., 1999; Lin, Orsmond, Coster, & Cohn, 2011; Pottie & Ingram 2008).

Autism spectrum disorder creates unique stressors for parents associated with problems surrounding communication, social interaction, behavioral issues, dependency issues, and life span care. Approximately 85% of those diagnosed with ASD will need lifetime care, which typically falls on the parents, for the remainder of their lives (Volkmar & Pauls, 2003). Further, given the amount of social marginalization and discrimination toward the disorder (Karst & Van Hecke, 2012; Wolf, Noh, Fisman, & Speechley, 1989), parents of autistic children often report an increase in alcohol and drug use, changes in career, as well as an overall lower reported quality of life (Kuusikko-Gauffin et al., 2012). For instance, parents of ASD children may put off life plans or become isolated from friends or family (Wolf et al., 1989), and report feeling excluded from education and change in typical home environments (Walsh, Mulder, & Tudor, 2013). Raising a child with ASD can also put temporal and financial burdens on the family, through healthcare, treatment, therapists, and accommodations. Mothers of children with ASD and other developmental disorders, for example, have been found to take off eight excess weeks in comparison to parents with children of other mental disabilities, reducing stability of a job and funds (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). This is further supported by research demonstrating that the economic impact on a family raising a child with ASD is approximately three to five million dollars above raising a typically developing child, and the estimate increases if the child's symptoms are more severe (Lord & Bishop, 2010).

Additionally, parents raising ASD children report lower emotional and psychological well-being (Ekas, Lickenbrock, & Whitman, 2010; Ekas, Whitman, & Shivers, 2009; Lin et al.; Pottie & Ingram, 2008; Tiba, Johnson, & Vadineau, 2012). For example, researchers have found mothers of children with ASD report higher levels of distress and lower overall quality of life when compared with mothers raising children with another intellectual disability (Olsson & Hwang, 2001). Research also shows elevated levels of parental mental health problems, specifically anxiety and depression, among parents of children with ASD, when compared to parents of typically developing children and children with other developmental disorders (Benson & Karlof, 2009; Gau et al., 2011; Olsen & Hwang 2001; Sawyer, Bittman, La Greca, Crettenden, & Harchak, 2010). Sharpley, Bitsika, and Efremidis (1997) found, for instance, that approximately 30% of parents of children with ASD experienced moderate to severe anxiety, approximately 20% experience clinically significant levels of depression, and 80% of parents of children with ASD report being “stretched beyond their limits.” Further evidence is provided by a meta-analysis which revealed that parents of children with ASD had significantly higher depression rates than parents of children with other developmental disabilities (Singer, 2006). Overall, research demonstrates that lower well-being is not attributed to one single factor, but a variety of factors, including an inability to sleep (Lopez-Wagner, Hoffman, Sweeney, & Hodge, 2008; Meltzer, 2011), relationship stress (Meirsschaut, Royers, & Warreyn, 2010; Rodrigue, Morgan & Geffken, 1990), being unable to control their child’s behavior (Davis & Carter, 2008), genetic factors (Hodge, Hoffman, Sweeney & Riggs, 2013), and being unable to accept the disorder (Parkes & Weiss, 1983).

Although several studies have examined the relationship between autism and the well-being of parents, no research has explored the prevalence of mortality-related concerns in this population. When a child with special needs is young, many parents fear whether or not the child will live (Zhou, Liu, Chen, & Yu 2008). However, with advancing age, this fear of mortality is redirected to concerns over

the care of the adult ASD child if something were to happen to the parents (Heweston, 2002; Krajewski, 2005). Utilizing terror management theory as a framework (Greenberg, Solomon, & Pyszczynski, 1986), one goal of the present study was to explore whether parents of children with ASD report greater concerns about death compared to parents of typically developing children.

### **Terror Management Theory**

Following a long line of existential theorists (Becker, 1973; Kierkegaard, 1847; Rank, 1924), terror management theory is a perspective in social psychology interested in how individuals manage concerns associated with the awareness of death (see Greenberg, Solomon, & Arndt, 2008 for a recent review). Specifically, the theory suggests that humans' awareness of death combined with their desire for life has the potential to create extreme anxiety or terror. Greenberg and colleagues (1986) suggest that there are two psychological mechanisms that help individuals handle the fear of mortality. These two mechanisms are cultural worldview validation and self-esteem (Greenberg et al., 1990, 1992, 1993, 1995). Cultural worldviews buffer the fear of death through the embracing of others with similar worldviews, and rejection of those who are in opposition to their worldviews (worldviews transcend death). Greenberg et al. (1990) found that when reminded of their own death, American participants gave positive ratings to those who praised their worldview, and negative ratings to those who disagreed with or threatened their worldview. Self-esteem is achieved when one feels as though he/she is aligned with his/her cultural worldviews, whereas low self-esteem occurs when an individual feels he/she has not achieved social norms or his/her desired worldview. For example, research demonstrates that those with high self-esteem are less effected by thoughts of mortality than those with low self-esteem (Greenberg et al. 1992, 1993; Harmon-Jones et al. 1997).

Recent studies have revealed that another coping mechanism in overcoming the fear of death is close relationships (see e.g., Mikulincer, Florian, & Hirschberger, 2003 for a review). For instance,

research has shown that reminders of death lead people to initiate interactions with other people (Taubman Ben-Ari, Findler, & Mikulincer, 2002), increase their desire to be part of a group (versus being alone; Wisman, & Koole, 2002), heighten feelings of personal competence and reduce fear of rejection (Taubman Ben-Ari et al.), and increase people's need for intimacy and commitment in romantic relationships (Florian, Mikulincer, & Hirschberger 2002). Furthermore, research has shown that attacking the integrity of a relationship increases the accessibility of death-related thoughts, just as threats to self-esteem and one's cultural worldview do (e.g., Harmon-Jones, Simon, Greenberg, Pyszczynski, Solomon, & McGregor, 1997). For example, having participants imagine either a separation from or argument with a romantic partner increases the extent of death-related thoughts and worldview defense (Florian et al., Studies 2 & 3; Mikulincer et al., 2002). Whereas a majority of research has focused on people's relationships with their romantic partners, more recent evidence has shown that parents also provide a terror management resource for their adult children (Cox et al., 2008).

Although the findings from several studies suggest that close relationships serve a death anxiety-buffering function, research has yet to examine mortality-related concerns in parents of autistic children. On one hand, it seems possible for ASD parents to report greater cognitions about death. For example, according to one parent, "What will happen to our son when I die? He's a 24-7 responsibility. He has limited fine motor skills. And his cognitive skills allow for limited speech and reading, but no understanding of money. His skill levels will always call for 24-7 care" (Krajewski, 2005, p. 342). On the other hand, however, social support has been identified as one of the most powerful predictors of psychological well-being among parents with ASD children (for reviews, see Beresford, 1994; Boyd, 2002; Glidden & Schoolcraft, 2007). Specifically, perceptions of the availability and quality of relationships with family and friends is associated with lower levels of distress (Ekas et al., 2010),

decreased negative affect (Weiss, 2002), and greater psychological and social health (Ekas et al. 2010; Montes, & Halterman, 2007). This suggests that perceptions of social support could buffer the effects of mortality salience on the well-being of parents of children with ASD. Given these divergent findings, the present study was exploratory in nature to examine whether parents of ASD children report greater concerns about death compared to parents of typically developing children. An additional goal of this research was to examine the extent to which heightened mortality concerns affect perceptions of meaning in life (i.e., psychological well-being) in parents of both ASD and typically developing children.

## METHOD

### **Participants**

The experimental group consisted of 74 parents (74 female; age range between 26-55 years,  $M_{\text{age}} = 39.15$ ,  $SD = 6.15$ ) of children with ASD from across the United States and Canada. Participants were recruited through flyers and internet announcements posted in the Fort Worth area; additionally, participants were selected through message boards (Facebook) and support groups on the internet. Of the participants selected, 63 of them indicated that they were married, 4 were single, 1 was widowed, and 7 were divorced. Further, 18 persons indicated household incomes less than \$40,000 per year, 22 individuals had incomes of \$40,000-\$75,000, and 34 persons earned \$75,000 a year or more.

Control group participants ( $n = 122$ ; 74 female; age range between 21-53 years,  $M_{\text{age}} = 34.21$ ,  $SD = 6.24$ ) were recruited through Amazon's Mechanical Turk (MTurk). A prescreen survey was administered to parents to ensure that their child was between the ages of 4-12 without an autism diagnosis. Participants were paid \$5 to complete the 1-hour survey, which was administered online. Twenty-one of the parents were single, 86 indicated they were in a relationship or married, and 15 participants were divorced. Fifty-five of the participants reported household salaries less than \$40,000,

39 persons indicated salaries between \$40,000-\$75,000, and 28 participants earned more than \$75,000 annually.

### **Materials and Procedures**

The study was conducted via an internet-based questionnaire. After giving informed consent, participants completed a survey consisting of various question topics. Survey materials were compiled and completed through Qualtrics, an online survey program. The content and order of the measures are described below.

***Cognitions about death.*** Participants completed a word completion task that determined the accessibility of death related thought in addition to the death concerns that the participants may explicitly report. Word fragment tasks are often used to measure construct accessibility (e.g., Tulving, Schacter, & Stark, 1982). In this section, participants were asked to complete the words with the first thing that came to mind. The words had options for neutral or death related terms, for example GR\_\_ \_\_, in which participants could complete the blanks with GRAVE, GRAPE, or GRADE. Participants who filled in high levels of death related words showed that the participant had death more cognitively accessible. In the present study participants were given 30 word fragments to complete, 5 of which were linked to death concerns; and death accessibility scores were calculated as the total number of death-related word completions. In previous research, this measure has been used to show death thought accessibility and aligns with lexical decision approaches (Hayes, Schimel, Arndt, & Faucher, 2010)

***Fear of death.*** Participants also completed a Fear of Death Scale (Templar, 1970). This scale asked explicit concerns about death, through participants responding to 15 true or false questions concerning the extent in which they feared death (e.g. “I am very much afraid to die”). Affirmative responses to each item were summed together to compute five scores of explicit worries about death:

fear of an unknown death ( $\alpha = .67$ ), fear of suffering ( $\alpha = .73$ ), fear of a lonely death ( $\alpha = .82$ ), fear of a negative death ( $\alpha = .57$ ), and a total death score (all items combined,  $\alpha = .83$ ).

**Satisfaction of life.** Participants then completed a Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985). The current study asked five questions to determine the participants' perception of their life satisfaction (e.g. "I am satisfied with my life" and "The conditions in my life are excellent"). Participants ranked statements on a scale from 1 (*Strongly disagree*) to 7 (*Strongly agree*) and scores were averaged to complete an overall satisfaction of life score ( $\alpha = .83$ ).

**Meaning in life.** Participants were then asked to complete a 10 question Meaning of Life Scale (Steger, Frazier, Oishi, & Kaler, 2006). The scale was designed to determine the participants' self-perception of the presence of meaning in their lives (e.g. "I understand my life's meaning" and "My life has a clear sense of purpose"), as well as the participants' perception of their search for meaning in their lives (e.g. "I am always looking for my life's purpose" and "I am seeking a purpose or mission for my life"). Participants ranked each statement on a 1 (*Not at all*) to 7 (*Very much*) scale, and scores were averaged to create two separate scores for presence of meaning ( $\alpha = .78$ ) and search for meaning ( $\alpha = .88$ ).

## RESULTS

**Concerns about death.** The first hypothesis examined whether parents of children with ASD reported greater concerns about death than control parents. The results revealed no significant difference between the two groups in terms of: death thought accessibility,  $t(194) = 1.40, p = .16$ , and four of the fear of death scales (total, unknown, suffering, and negative concerns),  $t(187) \leq 1.36, ps \geq .17$ . However, parents of children with ASD reported significantly fewer fears of dying a lonely death ( $M = .83, SD = .91$ ) compared to control participants ( $M = .44, SD = .74$ ),  $t(187) = 2.98, p = .003$ .

**Well-being.** The second hypothesis examined whether parents of ASD children reported lower well-being than control parents. The results found no significant difference between conditions on satisfaction of life,  $t(192) = .65, p = .52$ . There was, however, a significant difference between conditions on meaning presence,  $t(192) = 2.34, p = .02$ , and meaning search,  $t(192) = 2.72, p = .01$ . Specifically, parents of children with ASD reported greater present meaning in life ( $M = 2.44, SD = .55$ ) and lower search for meaning in life ( $M = 1.39, SD = .92$ ) compared to control parents (presence  $M = 2.19, SD = .80$ ; search  $M = 1.76, SD = .90$ ).

**Mediation of well-being by lonely death concerns.** To examine whether dying a lonely death mediated the effects of parent condition on well-being, I followed traditional steps for mediation (Barron & Kenny, 1986; Preacher & Hayes, 2004). Meeting the first and second criterion, parent condition was significantly related to well-being, as measured by presence and search, as well as death loneliness. The third step examined the relationship between death loneliness and presence and search while controlling for parent condition. Although there was no significant relationship between death concerns and presence meaning,  $b = -.07 (SE = .06), t = 1.16, p = .25$ , greater fear of dying a lonely death was associated with meaning search,  $b = .22 (SE = .08), t = 2.76, p = .006$ . The final step examined the relationship between parent condition and search for meaning in life while loneliness at death was in the model. When loneliness scores were entered into the model, the relationship between condition and well-being became non-significant,  $b = -.27 (SE = .14), t = 1.92, p = .06$ , suggesting full mediation (see Figure 1). Overall, these results suggest that parents of children with ASD report less fear of a lonely death, which leads to lower search for meaning in their lives.

## DISCUSSION

“... soon I won’t be available. Am I pessimistic about my time left? No, just realistic. I feel it, know it.

I wonder if my son does.”

- Bob Krajewski (2005, p. 343), father of an autistic child

In light of the aforementioned quote, the purpose of the present research was to examine the effect that raising a child with ASD has on one's fears of mortality. The current study revealed three significant findings. The first finding showed that parents of children with ASD reported significantly less fear of dying a lonely death than control parents. Second, the results revealed that parents of children with ASD reported greater meaning in their lives and less search for meaning in their lives than control parents. The final finding showed that death concerns mediated the relationship between parenting and well-being, with parents of children with ASD reporting greater presence and less search for meaning to the extent that they reported less fear of dying a lonely death. Overall, these results suggest that compared to parents of typically developing children, parents of children with ASD report fewer concerns about death which leads to greater psychological health.

These results suggest that raising a child with ASD can be beneficial by giving a greater sense of meaning to parents' lives. These findings are consistent with Montes and Halterman (2007) who found that though children with ASD create more stress in their parent's lives, that parents report higher levels of relationship closeness than parents of typically developing children. Future research should take into consideration Hoffman et al.'s (2009) research findings that parents of children with ASD see the diagnosis as a protective factor in their relationship, because parents do not blame the child for their behavioral issues. Future research should examine the protective factors such as social support, and how it affects parent's views of dying a lonely death. (Ekas et al., 2010; Faso et al.; Pottie & Ingram, 2008; Walsh et al). Overall, the current research implies new benefits in raising a child with ASD, which could be considered for parents of children with other disabilities, and used as further defense for parents facing difficult struggles with their child with ASD.

The current research also has important implications for work on terror management theory. Specifically, Mikulincer et al. (2003) argued that relationships serve an anxiety buffering function well beyond childhood. They point out that relationships are valued by every culture; cultures endorse the formation and maintenance of relationships, and many rituals have been developed to protect these values (e.g., greetings, marriages; Goffman, 1972). For parents, having children can help in the resistance against fear of death because a child helps continue a parent's cultural worldview, their genetic link, a connection to their social self (Fritsche, Jonas, Fischer, Koranyi, Berger & Fleischmann, 2007). Though studies have shown that mortality salience increases the number of children people intend to have (Wisman & Goldenberg, 2005), no research has been done on whether a developmental or intellectual disability increases or decreases the anxiety buffer that typically developing children create for parents. The current research is the first to find that there is a greater buffer concerning loneliness in death thought accessibility.

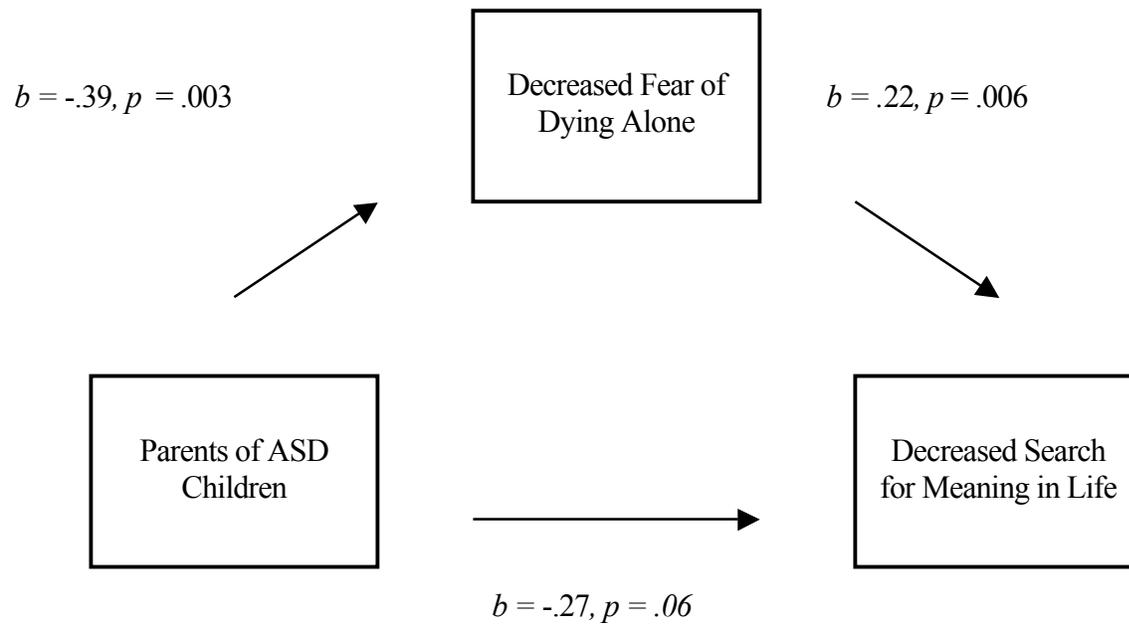
Although the current results provide insight about the relationship between mortality concerns and well-being among parents with autistic children, there are several limitations that need to be addressed. First, the data were collected via an online program (Qualtrics), which could result in both self-report errors as well as a lack of seriousness from participants. Future research could seek to collect the data in a face-to-face format. Secondly, the study collected data from twice as many control participants as parents of children with ASD. This could lead to incorrect implications because of the limited amount of experimental participants with children with ASD. Future research should seek to increase the number of participants with children who have ASD. Lastly, this experiment did not take into consideration individual differences among parents. Future studies could examine the attachment style differences in both ASD and control parents and determine if this has a larger effect on resiliency to fear of dying a lonely death. Specifically, if parent-child relationships are anxiously attached, this

could lead to an increase in mortality-related concerns and relationship needs in both control parents and parents of children with ASD (Mikulincer et al., 2003).

Despite these limitations, the current research is the first to determine the benefits of raising a child with ASD in relation to death concerns, meaning in life, and search for meaning in life. Findings suggest that raising a child with ASD is beneficial in both giving meaning to parents' lives as well as reducing their fear of dying a lonely death. The current study is the first to emphasize benefits of raising a child with ASD. Future support groups of parents raising children with ASD could emphasize these benefits as further coping techniques.

APPENDIX

Figure 1. Mediation analysis showing the role of the fear of dying alone on parenting ASD children and search for meaning in life.



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