



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

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