

Self-Reported Physical Health Outcomes of Caregivers Raising Very Low or Low Birth

Weight Children

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INTRODUCTION

As survival rates of pre-term and very low birth weight (VLBW) infants increase, so do concerns over the justification and ethics of intensive lifesaving care for the most immature of these infants (Singer et al., 1999). Parental input has come to be expected in decisions regarding life-sustaining treatment for critically-ill infants, which disproportionately affects preterm and low-birthweight infants (Singer et al., 1999). The ethical debate over lifesaving care raises questions regarding the outcomes of the child and their family as the child ages (Singer et al., 1999; Miceli et al., 2000). Research on the outcomes of children born prematurely and/or at low and very low birthweights indicates that the children are more likely to face mild to severe disability over the life course (Case & Paxon, 2002). The needs of the child with a disability affect the physical and mental health of the parents or caregivers in the long term, may increase the risk of divorce for married parents and decrease the likelihood of marriage between never married parents, and disproportionally affect the coping mechanisms of the family (Corman & Kaestner, 1992; Saigal et al., 2000; Case and Paxon, 2002). The unpredictable nature of the outcomes of the very low to low birth weight infants and their families fuels the ethical debate.

Past research has shown that child development is affected by social forces, in addition to physiological factors (Belsky, 1984; Miceli et al., 2000). The social forces that influence child development include the child's family and especially their direct caregivers (Barrera et al., 1986). In order to ensure the caregivers are capable of providing good overall care to the child, the caregivers need to be in good mental and physical health (Barrera et al., 1986). Premature or VLBW infants, however, can introduce a high level of stress into the caregiver's life across the life course, which may impair the caregivers from providing an environment conducive to the best health outcomes for the child (Belsky, 1984; Miceli et al., 2000). For example, the mental

health and wellbeing of school-aged children born preterm is correlated with the level of maternal psychological distress (Singer et al., 2007; Smith and Grywacz, 2014). In addition, caregivers of children with special health needs have been shown to have more trouble with activities of daily living and lower self-rated mental health as they enter midlife, when compared to caregivers of healthy children which may increase the burden of healthcare costs in a situation where costs are already high (Smith and Grywacz, 2014).

This paper addresses the questions surrounding the impact on caregivers' physical health, while addressing the intervening factors that may lead improved outcomes for these families. In particular, this paper examines the research question: Does raising a child born at a normal, low, or very low birth weight affect the self-rated physical health of the caregiver? With this question in mind, I hypothesize the following:

H1: The caregiver of a child born at a low or very low birth weight will report lower self-rated physical health than the caregiver of a child born at a normal weight, when accounting for sociodemographic factors and life event stressors.

H2: The caregiver of child with special health care needs will report a lower level of self-rated physical health, especially when the child was born at a low or very-low birth weight.

H3: A caregiver who perceives they are having a more difficult time raising a child will report lower self-rated physical health, especially when the child was born at a very-low birth weight.

H4: Having adequate social support and a greater sense of control over their child's medical care will improve the report of self-rated physical health of the caregiver, especially when the child was born at a very-low birth weight.

METHODS

Data and Participants

The 2016 National Survey of Children's Health (NSCH) collects national and state level data on the physical and mental health of American children between 0-17 years of age (U.S. Census Bureau, 2017). Information is collected on factors of health and wellbeing of children, including access and utilization of health care, receipt of care in a medical home, family interactions, parental health, neighborhood characteristics, and school and after-school experiences (U.S. Census Bureau, 2017). The 2016 NSCH is a new design, combining the National Survey of Children with Special Health Needs (NS-CSHCN) and National Survey of Children's Health. The analysis was completed using multiple regression in STATA 15, however, a path model is currently in progress for the paper.

RESULTS

Hypothesis 1 speculates that caregivers of children born at a low or very low birth weight will report lower self-rated physical health, once I have accounted for sociodemographic factors and life event stressors. Findings demonstrates that for caregivers, having a child born at a low or very low birth weight does not affect their physical health ($\beta = .014, p = .85$), however, having a child with special healthcare needs does lower self-reported physical health ($\beta = -.19, p < .001$) supporting hypothesis 2.

Hypothesis 3 posits that caregivers who perceive that their child is particularly hard to raise will self-report lower physical health. In the regression models with the interaction included, caregivers do not report significantly lower physical health ($\beta = -.03, p = .71$).

Hypothesis four postulates that having adequate social support and a greater sense of control over their child's care will improve the report of self-rated physical health of the

caregiver, especially when the child was born at a low-to-very low birth weight. The results further show that when a caregiver perceives a lack of control over the child's medical decisions, but states that they have had social support, they report lower levels of physical health ($\beta = -.49$, $p = .08$), in partial support of hypothesis four. As the amount of perceived control over medical decisions gets lower, even when buffered by social support, the caregiver tends to report lower physical health.

Implications

The research presented here shows that having a low or very low birth weight child does not impact the self-reported physical health of the child's caregiver later in life. If that child (or a child born at a normal birth weight), however, has special medical needs, caregivers will report lower physical health during the life course. The caregivers in this sample range in age from 18 to 75, with a mean age of 42.2, and the children range in age from zero to seventeen, with a mean age of 9.4, which gives one of the most comprehensive examples of the effects of both low and very low birth weight children, as well as those with special healthcare needs and their caregivers. Previous research has shown that children with special healthcare needs place a substantial amount of stress on their caregivers, which the results presented here suggest as well. Additional support from physicians, nurses, social workers, and other programs to help caregivers to improve stress management skills will improve both caregiver health and support a healthy environment for the child with special health care need to thrive.

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