

Parents of severely ill children see benefits as caregivers, says study

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Benefits often coexist with the negative and stressful outcomes for parents who have a child born with or later diagnosed with a life-limiting illness, says a recent study led by a researcher at the University of Waterloo.

While the challenges are numerous and life-changing and stress levels high, the vast majority of [parents](#) who participated in the Waterloo-led research reported positive outcomes as well, a phenomenon known as posttraumatic growth. The findings appear in the most recent issue of the *American Journal of Orthopsychiatry*.

"What is pivotal is the meaning the parents make—what it means to them to be a parent who is doing more than parenting: they are caregiving as well," said Professor Susan Cadell, lead author of the study. She is a professor in the School of Social Work at Renison University College at Waterloo. "For many parents this means learning a great deal about their child's illness, the treatment and sometimes it includes advocating for themselves and others in similar circumstances."

More than 270 parents of children under the age of 20 in Canada and the U.S. with diseases and conditions such as cancer, severe cerebral palsy and irreversible organ failure participated by answering a 15-page questionnaire.

On average, respondents spent more than 62 hours a week as caregivers, the majority said their employment status changed as a result of their

child's condition, and reported high levels of difficulty in managing cost. Still, caregivers reported growth, as measured by the PostTraumatic Growth Inventory (PTGI), a common tool used to measure positive aspects of stressful situations.

Out of a possible 126 points, with 0 indicating no growth at all, the parents reported an average of 62 points on the PTGI. Areas measured include relating to others, personal strength, appreciation of life and spiritual change.

"The findings indicate that there are a variety of positive aspects in a population where we think not much positive at all is happening," said Professor Cadell. "Our response rate was high because people wanted to talk about their children, families and relationships. This research has the potential to positively impact support for care-giving parents."

Researchers from six universities contributed to the study, including McGill University, the University of British Columbia, York University, University of Victoria and Nipissing University. The study looks at the first three years of data.

With the wealth of information collected during this study, including three more years of data, the research team plans to examine how posttraumatic growth changes over time. The Canadian Institutes of Health Research funded the project. A documentary film involving many of the families is also in the works for use in course work and outreach programs.

Provided by University of Waterloo

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