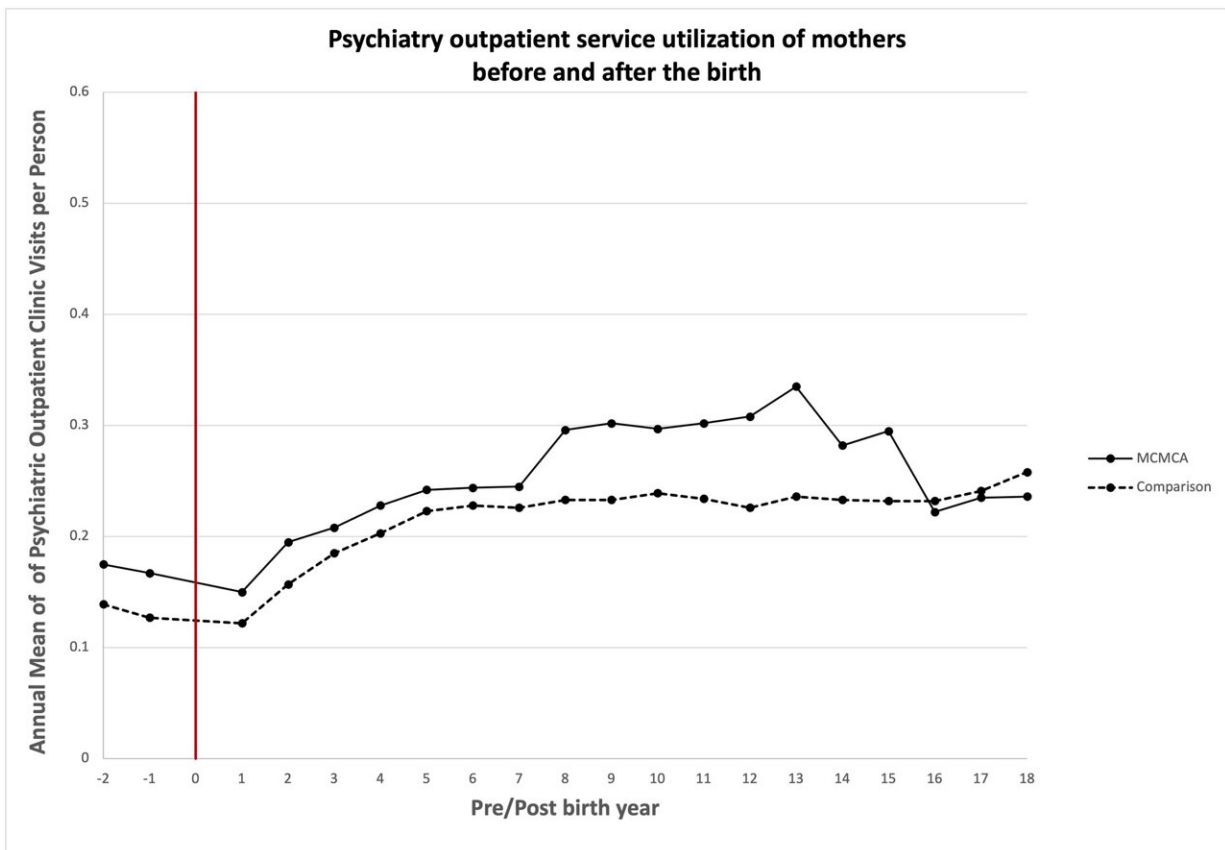


Mothers of chronically ill children seek more health services, study shows

April 13 2022, by Laurie Flynn



Unadjusted annual mean psychiatric outpatient service utilization before and after the birth during the follow up period. Credit: *PLOS ONE* (2021). DOI: 10.1371/journal.pone.0260962

Researchers at Stanford and Denmark's Aarhus University found that

mothers of chronically ill children tend to make greater use of health care services—particularly psychotherapy—to help them cope with the daily challenges of caregiving.

The impact of caring for a chronically ill child extends beyond the mothers' day-to-day struggle. "We're seeing just the tip of the iceberg," said Kyung Mi Kim, Ph.D., a research fellow at Stanford's Clinical Excellence Research Center. She and Nirav Shah, MD, a senior scholar at the center, were co-lead authors of the study, published in December in *PLOS ONE*.

"Our ongoing evaluation of employment outcomes indicates that the long-term physical and psychological challenges of caregiving take a toll on caregiving mothers' health and can force them to leave the workforce," Kim said.

CERC director Arnold Milstein; CERC affiliated scholar Eyal Cohen, MD, of the University of Toronto; and CERC senior adviser Henrik Toft Sørensen, MD, Ph.D., of Denmark's Aarhus University, were joint senior authors.

The researchers said they hope that a better understanding of the challenges faced by mothers of chronically ill children will lead to interventions that protect their physical and [mental health](#).

These could include longer paid maternity leave to support mothers' postpartum recovery and paid leave for [child care](#) when the caregiving burden is high. Such interventions could help a large number of mothers, as 2% to 3% of all babies born every year in the United States have congenital anomalies, which include Down syndrome and heart defects.

Danish data

Research examining the use of [health care services](#) by mothers of chronically ill children has been limited because of a lack of longitudinal data. For this study, the researchers turned to Denmark, one of few countries to rely on its national birth and medical registries to track health care services use over decades.

Because Denmark's national health care system fully covers primary, specialist, inpatient and mental health services, researchers were able to examine the long-term effects of caregiver burden without considering whether participants had access to care or the ability to pay for services, which can be factors in the U.S. health care system.

The sample included 23,927 mothers in Denmark who gave birth to infants with major congenital anomalies between 1997 and 2017, and a control group of mothers of unaffected infants. The births had been recorded in the Danish medical birth registry.

Major congenital anomalies are generally defined as structural or functional anomalies that are present at birth and have a dramatic impact on health and functioning.

The researchers learned that mothers of chronically ill children up to age six used inpatient services 39% more than other mothers, and mothers of chronically ill children seven to 13 years old used 14% more inpatient services.

Mental health care use was highest for mothers of affected children from seven to 13 years old: These mothers used 22% more [mental health services](#) than mothers of unaffected children, and this percentage was even higher for mothers at lower income levels, whose use of psychotherapy was 59% higher when the child was seven to 13 years old.

The greater use of health services translates to a significant increase in

cost: Per capita health care spending in Denmark was \$5,568 in 2019, meaning a 1% increase in health care utilization would lead to an increase of \$325 million annually for the country of 5.8 million people. Applied to the United States, a similar increase in health care use would have an even greater impact, considering that twice as much per capita is spent on health care in the U.S. than is spent in Denmark.

A look at employment

The *PLOS ONE* paper is the first of three studies by researchers from the center who are examining the impact of caregiving on mothers.

A paper expected to be published this summer will examine the effect on mothers' employment—a familiar theme during the COVID-19 pandemic, as the burden of caring for family members has fallen largely on women, forcing many to leave their jobs. A third study will examine the collective societal impact of mothers caring for chronically ill children.

"Developing care plans to provide long-term support and reduce financial and time burdens is critical," Kim said. "This is going to have serious long-term health and labor force implications."

More information: Nirav R. Shah et al, Mothers of children with major congenital anomalies have increased health care utilization over a 20-year post-birth time horizon, *PLOS ONE* (2021). [DOI: 10.1371/journal.pone.0260962](https://doi.org/10.1371/journal.pone.0260962)

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