Simple or moderate congenital heart defects might not impair fertility

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Women and men born with simple or moderate heart defects who

choose to have children are no more likely than others to experience infertility as adults, a study in Denmark suggests.

The researchers said it is the first study to examine the risk of infertility among women and men with congenital heart defects and offers reassurance to patients who are concerned about how the condition may affect their fertility if they decide to start a family. The results were published this week in the *Journal of the American Heart Association*.

With advances in treatment, many more children born with heart defects are living into adulthood, said the study's lead author, Dr. Louise Udholm of Copenhagen University Hospital. But little was known about the fertility of women and men born with heart defects.

"Published literature on fertility is truly limited, despite the fact that some—in particular female patients—express concerns about their fertility," she said. "The ability to create a family is of high priority for most people. So, we wanted to evaluate whether these patients are less fertile than other people in order to help them in their pregnancy planning."

The researchers analyzed the records of almost 1.4 million people born between 1977 and 2000—nearly everyone born in Denmark during that period. Of the 8,679 people born with a structural defect in their heart or major blood vessels, 51% had a simple defect, 34% had a moderate defect, and the rest had a complex or unspecified defect.

Among men with heart defects, 3.2% were diagnosed with infertility, compared to 3.6% of men without defects. Among women, 4.7% with a heart defect were diagnosed with infertility, compared to 5.6% of women without a defect.

When researchers separately analyzed infertility risk based on heart

defect severity, they were unable to determine whether fertility rates for people with complex defects differed from the general population. That's because the number of people with complex defects registered with infertility in the health records was too small. Complex defects may affect several parts of the heart and how blood circulates.

But regardless of a defect's severity, people with congenital heart defects who became parents had the same number of children as people born with healthy hearts—about two children on average.

The researchers also found that congenital heart defect survivors were more likely than others to be childless. This was true even among people with simple heart defects. Those findings suggest that even without symptoms or physical restrictions related to their condition, the diagnosis itself may have some psychosocial consequences related to decisions about childbearing, Udholm said.

"These results suggest that even more focus should be given to educational programs for adolescents with heart defects, or perhaps the parents in particular, in order to make sure that these young patients live their lives like their peers as much as possible with regards to relationships and sex and these more sensitive aspects of life."

Dr. Yonatan Buber is familiar with such issues. "Many of our patients come into a clinic stating in fact that they know that they cannot become pregnant, when it's absolutely not the case," said Buber, associate program director for the Adult Congenital Heart Disease Service at the University of Washington Medical Center in Seattle.

Growing up, many women with heart defects had been told by doctors that it may be dangerous to become pregnant, he said. But with appropriate medical care from a high-risk obstetrician, pregnancy is less risky than in the past for many women and their babies, depending on

the type and complexity of their heart defect.

Women and men also may fear passing the defect on to their children, the risk for which varies from as low as 2% if the defect's cause was unknown to as high as 50% if the cause was related to a genetic condition. However, when one parent is the only family member to have had a heart defect, the rate of heritability is low, estimated at 3% to 5%.

Buber, who was not involved in the study, called the research a "game changer" because it is the first to analyze these issues in a large population, and it included men who also have concerns about their fertility. Buber expects the results to affect the way doctors counsel their congenital heart defect patients about fertility.

The authors cite some limitations of the study. One is that Denmark's free health care system facilitates early diagnosis and treatment for children with congenital heart defects, so the results are only generalizable to populations with similar access to health care. Another is that they were only able to identify people with infertility if they sought care at a fertility clinic.

Another limitation is that the population in Denmark is not racially or ethnically diverse, Buber said, so the results may not be generalizable to a more diverse population.

Future studies, Udholm said, should delve deeper into the fertility of people with complex heart defects, which could not be determined in this study.

"It's in the last decade or so that women with more complex defects are allowed to embark on pregnancy, as a consequence of our improved treatment and management of these women," she said. "We expect that the number of women with complex disease embarking on pregnancy to

further increase in the coming years. So, we could perhaps repeat this study someday."