

NEWS

Community Newsletter: Controversy in stem cell journal, new autism trait inventory

BY CHELSEY B. COOMBS

23 MAY 2021

Hello, and welcome to this week's Community Newsletter! I'm your host, **Chelsey B. Coombs**, *Spectrum's* engagement editor.

First up this week, we're focusing on two papers in *Stem Cells Translational Medicine* that have garnered some attention online.

The first, "**Ethical issues concerning a pay-to-participate stem cell study**," comes from **Leigh Turner**, associate professor of bioethics at the University of Minnesota in Minneapolis, and **Jeremy Snyder**, professor of health sciences at Simon Fraser University in British Columbia, Canada.

@LeighGTurner and I have a new article in **@StemCellsTM** flagging a case where a for-profit clinic published in that journal without disclosing that participants in the trial paid to participate and that they were already selling the procedure in question
<https://t.co/Q7EQwu1jhq>

— Jeremy Snyder (@jeremysnyder) **May 19, 2021**

They write that a study on the use of stem cells to treat autism, published in the journal in 2019, violated the journal's conflict-of-interest and financial disclosure policies. (A 2019 *Spectrum* Deep Dive, "**False hope for autism in the stem-cell underground**," explored the controversy around the treatment). Among other things, the authors failed to disclose that participants had paid them

\$7,200 plus travel expenses.

“Readers of the article should know this as it can skew results, especially self-reported ones,” Snyder tweeted.

The trial registration, however, notes that participants must have "Adequate financial means to cover \$7,200 (US Dollars) plus travel expenses". Readers of the article should know this as it can skew results, especially self-reported ones <https://t.co/1Bv2SCMvhq>

— Jeremy Snyder (@jeremysnyder) **May 19, 2021**

Snyder wrote in his Twitter thread that the 2019 study’s publication increases the potentially risky and unproven treatment’s credibility.

He tweeted that the journal should investigate the issue and add a correction to the study, but “the damage is already largely done as this article continues to be used as a marketing tool to promote unproven stem cell interventions.”

The clinic sells this treatment and uses the journal publication to help bolster its credibility. Participants pay to participate in the study which then encourages customers to buy the treatment - and the line between these groups gets very blurry at best <https://t.co/WLRjLdSCFf>

— Jeremy Snyder (@jeremysnyder) **May 19, 2021**

Paul Knoepfler, professor of cell biology at the University of California, Davis, tweeted, “Should the SCI piece be retracted? I had concerns about it in 2019.”

Great work. Are the SCTM editors doing anything about the violation of their policies? Should the SCI piece be retracted? I had concerns about it in 2019: <https://t.co/NiE5XVPuEa> <https://t.co/jGYmwSKQ7S>

— Paul Knoepfler (@pknoepfler) **May 19, 2021**

The journal attracted more criticism for also publishing “Exploring new therapies for children with autism: ‘Do no harm’ does not mean do not try,” which cites the 2019 study “uncritically ... to make the case for publishing early stage clinical trial findings,” Snyder tweeted.

Ironically, in the same issue of @stemcelltm two section editors of the journal uncritically cite this very article to make the case for publishing early stage clinical trial findings <https://t.co/XzHokLEHW2>

— Jeremy Snyder (@jeremysnyder) **May 19, 2021**

The “Do no harm” paper’s authors — **Karen Ballen**, professor of medicine at the University of Virginia in Charlottesville, and **Joanne Kurtzberg**, professor of pediatrics at Duke University in Durham, North Carolina — are also section editors for the journal. They summarized the results of eight early-phase clinical trials, all published in *Stem Cells Translational Medicine*, that investigated the use of stem cells as a potential treatment in autistic children.

Ballen and Kurtzberg declared no conflicts of interest in their article, but Kurtzberg is an author of two of the studies cited.

“I find this article evasive and disingenuous — there’s a lot not being disclosed here,” Turner tweeted about the “Do no harm” article.

I find this article evasive and disingenuous -- there's a lot not being disclosed here -- but perhaps some of you have more critical responses. <https://t.co/8xsKy7QufN>

— Leigh Turner (@LeighGTurner) **May 19, 2021**

In a tweeted reply to Turner, Knoepfler wrote, “It’s important to keep reminding everyone that the data on cord blood for CP and autism are both very discouraging, even from Duke itself.”

Definitely. And it's important to keep reminding everyone that the data on cord blood for CP and autism are both very discouraging, even from Duke itself.

— Paul Knoepfler (@pknoepfler) **May 19, 2021**

Kristen Bottema-Beutel, associate professor of teaching, curriculum and society at Boston College in Massachusetts, also wrote a thread about the article. Regarding the deficit-model language used by the authors, she said, “Deficit descriptions of autism are used to justify harm, and the effects of perceived deficits on OTHERS are prioritized.”

There's a lot to unpack in this article promoting potentially harmful stem cell therapies for autistic people, but I want to note two things about what things are being done by the language used in the article. 1/8 <https://t.co/WMZNaQno1o>

— Dr. Kristen Bottema-Beutel (@KristenBott) **May 20, 2021**

Amy Pearson, senior lecturer in psychology at the University of Sunderland in London, England, tweeted, “I think the authors misunderstand the term 'do no harm.'”

I cant trust the opinion of someone who refers to autism as a 'disease'.
I think the authors misunderstand the term 'do no harm' <https://t.co/e4BRvnHbop>

— Amy Pearson (@DrAmyPearson) **May 20, 2021**

The next tweet thread of the week comes from **Michael English**, a postdoctoral researcher at the University of Western Australia in Perth. He tweeted about his new study in *Molecular Autism*, “The Comprehensive Autistic Trait Inventory (CATI): Development and validation of a new measure of autistic traits in the general population.”

“It is arguable that existing measures do not provide an ideal representation of the trait dimensions currently associated with autism,” English and his colleagues wrote.

That led to their development of the 42-question CATI, which anyone can take online.

Excited to share our new Comprehensive Autistic Trait Inventory (CATI)! A 42-item, modern measure of traits in the gen pop w/ subscales for sensory sensitivity, social camouflage, and more! Dev. and validation described in 3 studies in Mol. Autism. 1/2 -

<https://t.co/28HOZzf16j>

— Michael English (@mike_ology) **May 18, 2021**

Lucy Livingston, lecturer in psychology at Cardiff University in Wales, tweeted the study, asking why a camouflaging subscale was included in a measure of autistic traits.

Whilst being acutely aware of the need for better autistic trait measures, I am slightly confused why there is a camouflaging subscale in a measure of autistic traits? Camouflaging serves to reduce observable autistic traits, and is in no way a core component of autism... <https://t.co/A5nUhTO1hg>

— Lucy Anne Livingston (@Lucy_Livingston) **May 18, 2021**

English answered that “the autistic adults we consulted with in the early stages indicated it was important to them.”

Great point! This was hotly debated during development and peer review! We kept it because 1) the autistic adults we consulted with in the early stages indicated it was important to them, 2) it had unique variance in classifying autism and 3) it can be not administered if desired

— Michael English (@mike_ology) **May 18, 2021**

That's it for this week's Community Newsletter from *Spectrum*! If you have any suggestions for

interesting social posts you saw in the autism research sphere, feel free to send an email to me at chelsey@spectrumnews.org. See you next week!