MedicalXpress

Actress Kiruna Stamell debates gene editing with ethicist Dr. Christopher Gyngell

April 27 2017

Two papers published today by the *Journal of the Royal Society of Medicine*, debate gene editing and the health of future generations. Stage and screen actress Kiruna Stamell, who has a rare form of dwarfism, proposes that gene editing does not represent an improvement in healthcare; while Dr Christopher Gyngell, a research fellow at the Oxford Uehiro Centre for Practical Ethics, argues that provided it is well regulated, gene editing could greatly improve the health of our descendants.

Stamell writes that if gene editing is used simply to 'disappear' certain conditions and thus certain types of people, we must look at the ethics and impact of this more broadly and redefine what it means to be 'healthy' on a micro and macro level.

She believes that gene editing has far-reaching complications that affect more than individual health. She says: "Gene editing, if only available to certain groups, will drive social inequality further as those who can't afford it are left behind or discriminated against for having been born, when the opportunity was there for them to never have existed at all."

Stamell asks: "Will those people be left unsupported by a society that prefers to weed them out rather than allow them access and a share of its wealth and benefits?" She voices concern for future generations as variation is edited out. "Small differences begin to be perceived as greater ones and society's ability to adapt and accommodate differences will shrink" she says. She concludes that a community of people who

have forgotten how to adapt and embrace diversity can't be healthy for anyone.

Gyngell discusses the difficult and complex questions raised about disability, diversity and risks to human health. How to distinguish healthy forms of human diversity from disease and disability is, he writes, a subject of intense debate in philosophy but we should not let conceptual uncertainty be a barrier to the development of gene editing.

The use of gene editing in research, he writes, will greatly increase our knowledge of development and could lead to novel treatments for disease. He says: "Using gene editing to study early development could lead to a greater understanding of the causes of infertility and to better treatment options."

Gyngell goes onto describe how gene editing will be able to correct the mutations associated with fatal genetic disorders such as Tay Sachs disease and Duchenne muscular dystrophy. The incidence of these conditions can be reduced by using genetic selection techniques but, according to Gyngell, we may have reasons to prefer gene editing. He says: "Selection prevents disease by changing who comes into existence, whereas gene editing ensures those who come into existence have the best shot of living a full life."

Gyngell concludes that a case-by-case system of regulation for gene editing could work to both reduce rates of fatal genetic disease and avoid risking traits that may represent valuable types of diversity.

More information: Christopher Gyngell. Gene editing and the health of future generations, *Journal of the Royal Society of Medicine* (2017). DOI: 10.1177/0141076817705616

Kiruna Stamell. Why gene editing isn't the answer, *Journal of the Royal*

Society of Medicine (2017). DOI: 10.1177/0141076817706278