

FLOWERS FOR ALGERNON: THE ETHICS OF HUMAN EXPERIMENTATION ON THE INTELLECTUALLY DISABLED

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SUMMARY

Flowers for Algernon is a novel written in 1966 by Daniel Keyes. Since its publication, it has received significant critical acclaim, earning a Nebula science-fiction award, and was also adapted into a feature film.

Set in the 1960s, the novel follows the story of Charlie Gordon, an intellectually disabled man who lives a simple but happy life working a cleaning job at a local bakery. Charlie's life, however, faces an abrupt change when he is offered the opportunity to participate in a novel surgical procedure to improve his intellect.

Although he doesn't fully understand the risks of the operation, consent is provided on his behalf by his estranged sister and Charlie undergoes the experiment. The experiment is a success and Charlie develops intellectually at an alarming pace, soon surpassing the experimenters themselves. The rest of the book follows the, not all positive, changes that this intellect brings to Charlie's life.

The novel is set in a time when American scientific experimentation could often occur without fully informed consent. This article explores the ethical side of such experiments like the one performed on Charlie, namely if it is morally right to perform a potentially dangerous experimental procedure on someone who doesn't fully understand the risks, even if it will potentially help them.

Key words: *flowers for Algernon – ethics – human experimentation – informed consent – intellectual disability*

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Flowers for Algernon is a science fiction short story first written by Daniel Keyes in 1958, later adapted into a full novel in 1966. The book has received numerous awards and been adapted into an Oscar-winning film (Charly 1968).

Set in mid-1960s New York, the story follows Charlie Gordon, a 32-year-old man who suffers from intellectual disability due to phenylketonuria. At the beginning of the book, Charlie lives a relatively content life, doing odd jobs at a local bakery where he has a handful of friends, and he lives in lodgings. Charlie's life changes when he is given the chance to participate in an experimental surgical procedure which offers the chance of curing him of his intellectual disability. Consent for this experiment, which had only been performed in mice (some of which ended up becoming mentally disturbed) is given by Charlie's estranged sister, and the procedure is performed.

Initially, the results seem positive. Charlie quickly begins to develop intellectually, expanding his knowledge by reading an array of scientific textbooks. Before long, his intellect surpasses that of the doctors who performed the experiment on him. Sadly, the changes in Charlie bring with it significant problems in his professional and personal life. At his job, he realises that his so-called friends had in fact been exploiting him and making fun of him all along. After they cannot cope with his changes, he loses the job he loves. Although his intellect increases greatly, there is not a matching increase in his emotional intelligence and social skills, causing him great problems in romantic relationships, friendships and work relationships.

Thus, despite his intelligence, Charlie is left in a despondent state, with no true friends. His problems continue when he realises that the surgery has not been successful, and he is beginning to lose his intellect, slowly reverting to his initial intellectually disabled state. The book concludes with a dejected Charlie checking himself into a government home for the mentally disabled, where he will live out the rest of his days, with lower social function than at the start of the book.

The story highlights several ethical issues regarding the treatment of the intellectually disabled. Before the start of the experiment, Charlie lacked the intellectual capacity to consent to such a dangerous surgical procedure. While the risks were briefly explained to him by the scientists, it is clear from his own descriptions that Charlie had very little understanding of what the doctors were saying to him and as such was unable to provide informed consent.

It may be tempting to argue for the utilitarian "the ends justify the means" approach, namely if Charlie's intellectual disability could be cured, it is in his best interests to perform the procedure even if he cannot fully understand it. However, this does not consider the fact that this procedure was completely experimental and untested, and held severe risks for Charlie. Indeed, problems caused by the potential disparity between Charlie's intellectual and emotional development were not considered as important by the experimenters, and were a source of significant distress for him throughout the book.

Popular literature provides an accessible medium through which readers may access and consider many

key social issues which hold relevance in the world around them, that they otherwise may not encounter in their day to day life. Indeed, for many readers of *Flowers for Algernon*, this may be the first time they have considered in detail the potential implications of experimentation on the intellectually disabled. It is thus important that such books provide a positive message towards these readers, who may use the books they read to form opinions on these issues. *Flowers for Algernon* is successful in this regard in that it by no means attempts to sugar-coat the portrayal of the detriment that this unethical experiment has brought to Charlie's life, and the grim note on which the story concludes as Charlie faces the rest of his life in a care home serves as a miserable reminder of the injustices that have been committed against him.

Taking place in the 1960s, *Flowers for Algernon* is set in a time when unethical, government-sponsored human experimentation occurred in the USA, and before any robust laws regarding informed consent were in place. One damning example is the notorious Tuskegee Syphilis Experiments performed between 1932 and 1972, wherein unsuspecting and unconsenting African-American men who were told that they were receiving free health care were in fact injected with syphilis, so that the experimenters could observe how it spread in a human population (Paul & Brookes 2015). As such experiments were brought to the public eye, by the mid-1970s there was a demand for human research to be conducted only when participants were able to give fully informed consent and were able to understand the risks that any experiment may pose to them. These demands culminated in the publication of the 1979 Belmont Report, a set of guidelines outlining the limits to which human experimentation could be ethically

performed, and the process by which fully informed consent could be attained (Hammer 2016).

Certainly, by the ethical standards we hold today the experiment performed on Charlie, a dangerous and untested experiment on an individual who did not have the capacity to understand the risks, would be considered as gravely unethical. By demonstrating in unflinching detail the destructive effects of this unethical experiment on Charlie's life, *Flowers for Algernon* provides us with a vital lesson of the grave importance of demanding fully informed consent for human research throughout the world, and demonstrates that to compromise ethics using the excuse of the advancement of science is unethical and entirely unacceptable.

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Contribution of individual authors:

Nishan Ghoshal drafted the text,

Paul Wilkinson conceived the project and supervised it.

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