

New ethical guidelines needed for dementia research

March 29 2010

How do we handle the ethical dilemmas of research on adults who can't give their informed consent? In a recent article in the journal *Bioethics*, ethicist Stefan Eriksson proposes a new approach to the dilemma of including dementia patients and others with limited decision making capabilities in research.

There is a need for research on persons with impaired decision making, for example [dementia](#) patients. Without their participation we stand to lose knowledge necessary for future treatments that can benefit these groups. There are ethical guidelines to guard their interests, but they are somewhat ill-guided, says Stefan Eriksson, associate professor of research ethics at the Centre for Research Ethics & [Bioethics](#) (CRB).

"We are sometimes led to believe that these guidelines conclusively state that research on these groups is permitted only in exceptional cases, but they don't," he says.

According to Stefan Eriksson, today's guidelines are often arbitrary. On one hand, research that benefits some groups, for example one's own age group, is allowed. On the other hand, research that benefits other groups, for example one's own children or community is not allowed. The previous will or interests expressed by person has little or no weight in these situations.

Another problem that Stefan Eriksson highlights is that some ethical standards simply make no sense for these groups. For example, the idea

of a 'minimal risk standard' builds on the idea that there is something ordinary or routine about the risks we take in our daily lives. Such risks should then be acceptable in research as well. This kind of reasoning doesn't work for someone with for example Alzheimer's. The same is true for 'very slight impact' and 'routine examination', notions that doesn't translate well to a person with dementia who might very well react in a very different way than a person without dementia.

"The guidelines that researchers act according to allows for vulnerable persons to be exploited," says Stefan Eriksson.

Instead of trying to translate the norm to those who fall outside it, we need to address the real issues at stake and re-write the guidelines that apply today Stefan Eriksson says. We need to rid them of notions of exceptionality, minimal risk and group beneficence. We also need to monitor this kind of research more closely and provide legal obligations to compensate for any injuries suffered. He concludes: "But we also need to consider other issues, such as how surrogate decision-makers can be of use to these persons and how to find ways to estimate a dementia patient's capacity for autonomy. We need to continue the debate and do more research on the ethics of research on persons with limited decision-making capacity."

More information: The article is published at www3.interscience.wiley.com/jo.../123303187/abstract

Provided by Uppsala University

Citation: New ethical guidelines needed for dementia research (2010, March 29) retrieved 18 April 2024 from <https://medicalxpress.com/news/2010-03-ethical-guidelines-dementia.html>

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