Advance Research Directives: Avoiding Double Standards

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Abstract

Background: Advance research directives (ARD) have been suggested to facilitate research with incapacitated subjects, in particular in the context of dementia research. However, established disclosure requirements for study participation raise an ethical problem for the application of ARDs: While regular consent procedures call for detailed information on a specific study ("token disclosure"), ARDs can typically only include generic information ("type disclosure"). ARDs, therefore, run the risk of introducing an ethically problematic double standard.

Methods: This paper provides an ethical analysis of ARDs, taking into account the results of numerous empirical studies that have been performed so far. It will be argued that a revised understanding of informed consent can allow for context-sensitive disclosure standards. As a consequence, ARDs that include "type disclosure" can be acceptable under suitable circumstances.

Discussion: Such an approach raises objections, two of which are especially important. A thorough examination shows, however, that they are not sufficient to justify a rejection of the approach.

Conclusion: The approach presented in this paper avoids introducing a double-standard for particular types of research such as dementia research. It is, therefore, more suitable for the implementation of ARDs than established approaches.

Full Text

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