



Review Article

Research and the elderly: Do we need fair practices of ethics?

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ARTICLE INFO

Article history:

Received 18-05-2023

Accepted 10-07-2023

Available online 08-08-2023

Keywords:

Responsible Conduct of Research

Legal rights for Elders

Ethical principles of elderly research

ABSTRACT

Changing demographics have brought a dramatic increase in the need for research in the health care of the population, and understanding and countering opportunities and challenges presented by an aging population, and the process of aging, for enhancing the positive aspects of aging. It is also envisaged that the knowledge brought through research on the elderly has a large potential for improving individual lives and society. Since the elderly population represents a vulnerable group, it is thus required that research is conducted following ethical principles and proper protocols. This article examines various aspects involved in evidence-based research on the elderly.

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1. Introduction

Evidence-based research involving the elderly had become a common practice in conducting research in the recent past owing to population aging, chronic illnesses, dementia, post-COVID-19, and related issues. Of course, this interdisciplinary and collaborative research is very useful in terms of information and bringing the best practice outcomes in terms of elderly service planning and care. Research involving older adult participants takes the form of surveys, observational studies, or clinical trials in various healthcare settings.¹ It has to be understood that senior citizens are considered vulnerable, even if an elderly person is physically able to care for himself or herself, and holds full control over his or her mental capacity. It is because they are at a greater risk than normal persons for abuse in many forms, especially those who are ailed, weakened or frail, demented, and unable to fight for themselves or to keep track of their incidents in particular. So, the matter of safety and the protection required for the research

participants necessitates that the investigation should be carried out with proper consideration of ethics and standards involving human rights.² Many countries have developed guidelines for researchers while conducting studies with human subjects. Even though there are some similarities specific to the discrete country in terms of those directions, the common factor persuading behind each of it is the welfare of the potential research subjects.

2. Ethical Principles Guiding Research in Elderly

The primary objective behind the guidelines or recommendations involving elderly subjects is the protection of the research subjects from any type of harm, whether it is physical, mental, emotional, or social.³ The central core of ethical principles is mentioned in the Belmont Report: respect for persons, beneficence, and justice.³ While dealing with the conduct of research involving participants who are considered vulnerable, researchers might come across or will find themselves in a position of increased responsibilities, outside the scope of their research project.⁴ They should maintain the integrity

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of the research and justify their approach while dealing with circumstances involving unforeseen ethics issues (e.g., elder abuse).⁴ In such situations, they can approach their research ethics committee as a valuable resource for advice and guidance.

2.1. Justice

Justice refers to the non-discrimination of the elderly in their care, valuing humans equally, and trying to gain their rights as human beings.⁵ Regardless of age, culture, religion, and medical conditions, the elderly subjects must be provided with equal rights in receiving treatment and care facilities similar to other age groups.^{6–8}

2.2. Beneficence

Beneficence refers to the duty to do good and requires that the action being contemplated will result in an actual benefit to the patient.⁹

Nonmaleficence refers to the duty to treat individuals fairly (free of bias) and necessitates that the risks of harm from an action are minimal or do not outweigh the potential benefits.⁹

Justice requires that the benefits and burdens are borne as equally as possible across groups.¹⁰

3. The Role of the Ethics Committee

The research involving elderly subjects should be conducted with the permission of the Research Ethics Committee with established protocols and guidelines to ensure a robust and ethical research culture.¹¹ The principles to be borne while performing such research include protecting privacy, maintaining confidentiality, and respecting the autonomy and integrity of the research participants. Even though complete anonymity may not be possible in terms of research findings, the information collected from the participants must be protected so that it is not misused.¹¹

All research with elderly subjects should be conducted with strict adherence to the ethical principle of doing only good, and the obligation to avoid harm (principle of beneficence and non-maleficence), respecting the privacy of the research subject by keeping things confidential, ensuring the informed consent from the participant, and protecting the rights of individuals or social groups who are considered vulnerable or at risk.^{10,11} The research activities outlined in the project should undergo a thorough review process to ensure that the human rights are protected while conducting the research.¹² The sponsorships, affiliations of the researchers, the incentives for participation in the research, source of funding and clinical trials for any commercially-driven research, etc. to be evaluated and monitored.^{12,13}

4. Confidentiality and Privacy

The identity of the elderly individuals should be kept confidential so that the participant cannot be identified throughout all the stages of research including while publishing the research findings. Any unauthorized access to the research data should be restricted and their privacy is safeguarded.^{11,14}

5. Informed Consent

The core aspect of conducting any research involves obtaining voluntary consent within the legal capacity of the subject without any coercion, fraud, deceit, or any other elements of force or falsification. The subject who is participating should be able to comprehend and need to possess sufficient knowledge of the research, its risks and benefits, the nature of the research its purpose, duration, etc. This is particularly a priority when research is done with certain therapies.¹⁴ It is also necessary that any questions raised should be clarified and any misunderstandings are avoided. The elderly also needs to have a right to withdraw from the research at any time they wish.¹² It has to be remembered that in conditions where the consent cannot be obtained in written form, a formally documented and witnessed consent, which is non-written must be generated to protect the researcher.¹³

Challenges to obtaining informed consent might appear in circumstances while the elderly are being cared for by caregivers when they are institutionalized if they are dependent, or if there is a decrease in their cognitive capacity.¹¹ Apart from that, the health of the elderly may be compromised with multiple comorbid conditions, communication difficulties and diminished mobility.^{15,16} If it is decided that the patient lacks sufficient capacity to appreciate the risks and benefits of the procedure and make an informed, reasoned choice, a surrogate decision maker is identified.¹⁷ In such conditions, it may be necessary for the researchers to seek the cooperation of the family or formal caregivers to conduct the research.¹⁸ The ethical principle of justice exists in such conditions, especially when it comes to the communication of research findings to those who had contributed to the research, either directly or indirectly.¹⁹

6. Research Project Which is Scientifically Sound

The research should have an objective and set of procedures which are set to achieve the research's aims. It is important that considerations about the well-being of the human subject precedes and will be a priority when the researcher conducts an experimental study or a quasi-experimental study.¹⁴ The research should be conducted only in circumstances in which the participation of human subjects can be justified and when the proper conditions are ensured.^{12,13}

7. The Qualifications of the Investigators

The research should be conducted by proper personnel who are qualified to conduct the scientific research, with the permission, guidance, and approval of the ethical review committee. The highest degree of skill and care is required while conducting the research and they are obliged to report any occurrence of adverse events to the ethics committee.^{12,13} It may be also necessary that training for the investigator (Responsible Conduct of Research or RCR) may be required in certain countries and it is increasingly suggested and recommended.¹⁴

8. Conclusions

To conclude, there are certain factors which is generally considered while performing research on elderly subjects. The prime reason behind establishing protocols and sound scientific practices and legislations involving elderly research is for safeguarding the participants from any probable injury or harm, and protecting their rights while adhering to the ethical principles of beneficence and non maleficence, justice, and respecting the autonomy of the subjects. The elderly population represents a vulnerable group of people, who may need a more sensitive approach and require special precautions if they are facing any physical, mental, or cognitive concerns or challenges, exposing them to the risks of participation in the research project.

9. Source of Funding

None.

10. Conflict of Interest

None.

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Cite this article: John B. Research and the elderly: Do we need fair practices of ethics?. *Ann Geriatrics Educ Med Sci* 2023;10(1):3-5.