

Case-Report: Autonomy and Self Determination of an Elderly Population in South Brazil

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Abstract

Some elderly members of a small community in the state of Rio Grande do Sul, Brazil were victims of fraudulent behavior by a group of criminals. It happened shortly before the development of a research project that evaluated quality of life and decision-making capacity. Such a crime was a significant trauma for the victims and, as a result, the participants of the research refused to sign the Informed Consent Form. This case serves as background for supporting the distinction – sometimes confused in the literature – of emerging issues in the field of bioethics: ‘autonomy’ and ‘self-determination’. Ironically, although they had autonomy to decide to take part in the research, they were in fact not fully prepared to exercise their self-determination, since they were not able to sign a document to support their choice. Also, draws attention to the difficulties of obtaining scientific data from vulnerable populations.

Keywords: Autonomy; Bioethics; Elderly; Self-determination; Vulnerable population

Introduction

While the demographic transition leads us to a future of long-lived individuals, society seems to increasingly reduce the capacity of the elderly, underlining their fragile and dependent aspect. We can even hear about a “fourth age” or the “age of dependence”, especially coming from those who have not learned to respect the complex characteristics of the aging process yet [1].

For being one the fastest growing age group worldwide, research with elderly deserves special attention, should point to results of an independent and autonomous life, healthy and full of happiness.

The Complex Bioethics includes rational and non-rational issues when evaluate the adequacy of a situation and the approach may help, serving as a framework in the search for the adequacy of actions justification. Affectivity, including bonds and desires, belief systems and values, expressed as traditions or as interests are considered too [2].

Those who most need protection and access to the benefits of new technologies provided by research are also those most likely to be exploited [3]. Vulnerable subjects are willing to underestimate the potential risks and maximize the benefits offered, using different criteria and values when compared to subjects less vulnerable [4].

The goal of this article is to report an unexpected and real situation experienced during a research, to illustrate the differences between two different concepts, widely studied in the bioethics field: autonomy and self-determination.

The paper describes, first, the survey’s population and the conditions where elderly were exploited. Therefore, briefly, we present the methodology conducted with the elderly groups, permeated with discussion based on relevant literature and ending pointing to some conclusions that may be valuable for researchers.

Methodology and Case Report

During the activities related to a master’s course in Biomedical Gerontology at the Pontificia Universidade Católica do Rio Grande do Sul, Brazil, the researcher and her tutor developed a research project with elderly people from a small town of German colonization. The town is located in the Taquari valley and comprises mainly German

and Portuguese descendents, with an estimated population in the year 2009 of 19,059 inhabitants.

The project aimed to evaluate the quality of life and the decision-making ability of elderly that participated in socio-therapy groups (“elderly groups”) using two questionnaires. The WHOQOL-OLD evaluated the quality of life of aged individuals and the Questionnaire of Psychological and Moral Development measured their decision-making ability. Both questionnaires were printed and delivered to the participants along with the Informed Consent Form, which was approved by the Research Ethics Committee of the Pontificia Universidade Católica do Rio Grande do Sul. This form took into account all important points that assured protection and correct information about the goals of the research that would be conveyed to the participants. In developing this research, support was sought from the Health Department and the City Council for the Elderly.

In order to recruit individuals to participate in the project, the researcher contacted by telephone the president of each group of seniors to fix an appropriate date to interview the participants.

After the first phone contact the researcher noted a certain resistance from the president of the group. An additional difficulty was encountered: the president had difficulties expressing herself in Portuguese (most of the inhabitants of that location use a local German dialect). During the phone call, the researcher introduced herself as physiotherapist, briefly explained the goals of the research, and mentioned the support by the local City Council for the Elderly.

The first visit left the group uncomfortable and the president made it clear that they could answer any questions but would not sign any sort of documentation.

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The president explained the situation with certain regret, since she seemed to be convinced that the researcher did not mean any harm or pose any sort of menace to the group. Finally, she told the story of a deceitful action by criminals and the financial damage caused by them, supported by a document signed by a considerable number of elderly individuals.

In September 2007, before our research began, a group of criminals defrauded several rural communities. The fraudulent behavior proceeded as follows: they managed to illicitly obtain the address of retired persons from the database of the Social Security Department and introduced themselves to the potential victims as physiotherapists and social security agents. In order to get the signature of the retired, they presented a "miracle pillow", offering the product in the form of lending and, after a certain time, one could purchase the product or return it. The product promised healing properties in the prevention of heart and circulation diseases, as well as insomnia and depression.

In face of such marvelous effects, the criminals asked the elderly to sign a receipt. This document, in fact, was not a receipt, but a "consigned credit" form. This is a type of loan granted to people who are retired, and for which the deduction of monthly payments is made directly from the pension payments of the person concerned. The same document appointed the criminals as beneficiaries.

The scam had nationwide repercussion, including stories broadcasted by major national news shows all around the country. The general advice given to the population in that town was to avoid contact with strangers offering something or asking for signing any document. Thus, the researcher could understand the attitude of the elderly group and requested support from the president of the City Council for the Elderly, a person who enjoyed respect and recognition among the community. With the presence of the president, a new approach was adopted by the community, enabling the interviews and the signature of the consent form.

Discussion

The present paper, presents only the unexpected situation detected during the informed consent process in a sample of 133 seniors. They used to meet twice a month to share experiences and promote entertainment activities among elderly who lived in the neighborhoods.

The full results of the research project will be divulged in other future papers, but some results are useful for the understanding of this case report. The elderly groups demonstrated a good performance in the moral-psychological development scale used to infer personal autonomy. These results showed that all of them were autonomous persons, autonomy being understood as the capacity to decide among different alternatives in their best interest.

Although all human beings have the same dignity, autonomy – and, therefore, vulnerability – differs considerably [5].

It is important to review some of the key concepts related to the consent process, specially autonomy and self-determination, in order to understand how the elderly have decided to participate in research without having to sign any document.

Immanuel Kant, in his categorical imperative introducing the notion of autonomy, established:

"Treat others and oneself, never merely as means, but always at the same time as an end in himself" (Kant I, 1956, page 101) [6].

Self-determination is related to free will, and in this regard, John Stuart Mill wrote:

"Over himself, over his own body and mind, the individual is sovereign (p212)" [7].

In another citation, Mill states that:

"Power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others (212.)" [7].

After Tom Beauchamp and James Childress's [8] Principles of Biomedical Ethics, the principle of Respect for Persons - proposed in the Belmont Report [9] - was commonly assumed as Autonomy. Respect for persons is a wider concept than autonomy, because it involves, at least, privacy and confidentiality.

The differentiation between autonomy and self-determination must be assimilated, since autonomy could persist even without self-determination [10].

The ideas of both John Stuart Mill and Immanuel Kant about self-determination and autonomy support the interpretation of these unexpected data.

We took an adverse situation during the beginning of the research and used it as background in order to demonstrate that, even in a situation where the elderly were restricted in their self-determination, autonomy remains. While the elderly were able to verbalize their intention to participate in the study, in fact, they were exercising their autonomy. When they said it was not possible to sign a document following family's order, renounced their self-determination.

Affective bonds play an important role in the decision-making process, especially those related to family [11-14]. During the informed consent process, the potential elderly participants refused to participate in the study, if it were necessary to sign any kind of form. They justified their refusal to sign a document due to instructions established by their families, specially their sons and daughters. Signing the informed consent form was necessary to document their consent.

In the community studied, an important cultural trait is that multigenerational families usually live in the same house. Adult members of the family assume a caregiver role and, in the context, they prohibited elder family members to sign any document without their presence and approval. They suppress their parents' self-determination in order to protect them from future situations like the one where swindlers took advantage of the good faith of the elderly. On the other hand, the elderly asserted their autonomy, showing interest in participating, since it was not necessary to endorse their participation.

Based on the concept where the vulnerable are those whose autonomy, dignity and integrity may be threatened, the prohibitory attitude assumed by the family must be considered along with the individual wishes of the elderly [15]. Family well-being, in order to prevent harm, prevails over the self-determination of elderly individuals. This decision, in the context of a risk derived from a fraudulent behavior of criminals, expresses a protective behavior by the adult members of the family and not a destitution of the seniors' will.

With reduced autonomy comes increased vulnerability, implying extra attention to the protective dimensions. The changes associated with aging sometimes involve perceptions of incompetence or feelings of reduced self-determination – two factors that are known to affect motivation. Autonomy and choice should enhance self-determined extrinsic motivation: the individual experience a sense of purpose and direction in the performance of activities that may not be inherently interesting – for example: exercising, self-care [16]. An isolated notion of autonomy and a 'group-based' notion of vulnerability are

not adequate [5]. The policies that now guide human research focus on the protection of human subjects, making informed consent the centerpiece of regulatory attention [17].

Conclusion

This case report requires a discussion between the autonomy and self-determination concepts and, although some literature still refers to these two concepts as synonyms, they must be categorized. The sample demonstrates the ability to make decisions and considers autonomous individuals who, as a consequence of a traumatic episode, were deprived of self-determination by their families.

The concept of autonomy recognizes the human capacity of self-determination. Autonomy as a capacity of persons must be distinguished from autonomy as a property of actions and decisions (self-determination).

Carrying out research with vulnerable groups is an issue that Bioethics has sought to clarify, ensuring a safe field guided by ethics to serve human beings and headed for the advancement of science.

The consent process must be appropriate for vulnerable populations, taking into account and, above all, respecting their beliefs and frailty. Researchers must rely on the community support network - which is a reference in small communities - to overcome obstacles that may arise in the course of research.

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