

ORIGINAL ARTICLE

Disclosing non paternity in genetic counselling: in Italy the law overcomes the bioethical debate

Luciana Caenazzo, Pamela Tozzo and Daniele Rodriguez

Department of Environmental Medicine and Public Health, Legal Medicine Unit, University of Padua, Padova, Italy

ABSTRACT

Nowadays, the frequency of children identified as being biologically fathered by someone other than the man who believes he is the father is such that, in the field of genetic counselling, it is likely to encounter cases of false paternity. The false paternity information, neither requested nor expected by the families in many cases, seems to regard only the “father” of the family but has repercussions for the entire family. By now, it has been accepted that genetic information is, by its nature, both individual and familial.

The ethical-deontological debate centres on whether or not to inform the family about the necessity of a paternity test during the counselling and the counsellor’s duty to reveal the results.

In this paper, we analyse the Italian legislation on medical professionals’ position concerning the doctor’s role in genetics counselling: recent Sentences by Italian Courts and The Italian Personal Data Protection Code have underlined that the counsellor has to give complete information to the people involved, also regarding the possibility to disclose a false paternity, to enable both parents to choose whether they want to know the truth. Because of these statements, it seems that in genetic counselling the respect for the “client’s autonomy” is today prevalent in Italy, not only from an ethical-deontological point of view, but above all, from a legal one.

Keywords:

legislation as a topic, medicine, paternity, genetic privacy, informed consent.

INTRODUCTION

Misattributed paternity or false paternity is the condition in which it is assumed that a woman’s partner is the biological father of a child but, in fact, he is not. Nowadays, the frequency of misattributed paternity has increased to the extent¹ that health-care professionals can sometimes discover cases of false paternity during their activity, in particular during genetic counselling.

In the field of consulting, information regarding the possibility to discover a misattributed paternity is not

requested by families nor expected by them. This information, which seems to regard only the “father” of the family, actually has repercussions on the entire family. In recent times, it is frequent that a family asks to a forensic genetic laboratory to perform paternity testing, because of the possible doubts coming out from prior genetic counselling results. The request of a paternity test has become much easier since the appearance of websites which offer internet paternity testing without great limitations.

By now, it has been accepted that genetic information is by its nature both individual and familial.² In this article, we will consider the family as a whole, formed by partners (both parents) and the child involved in the consultation.

Based on our experience of the request of paternity testing by families involved in genetic counselling, and considering that we are involved in ethical-deontological debates about patient’s information and consent, with this work we will point out how the Italian juridical context has recently overcome the bioethical debate about counselling behaviour in cases of discovering misattributed paternity, considering some recent Sentences and The Italian Personal Data Protection Code which affirm the duty to inform patients about familial implications during genetic counselling.

THREE ASPECTS OF THE BIOETHICAL DEBATE ON DISCLOSING MISATTRIBUTED PATERNITY

The counsellor’s client(s)

According to what is reported in literature, both parents and the child are the counsellor’s clients.^{2,6} In contrast with other kind of medical information, which pertain primarily to individuals, information given by molecular genetic testing and/or pedigree analysis necessarily has implications for biologically related members of the family. The goal of counselling is “to promote client autonomy, [to help clients] understand their options and choose a course of action that is most appropriate to them in view of their risk and their family goals and act in accordance with that decision”.⁷

According to the NSGC (National Society of Genetic Counsellors), counsellors should “enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences” as well as “maintaining information received from clients as confidential, unless released by the client or disclosure is required by law”.

According to what is reported in guidelines on ethical issues in medical genetics⁸ it is “vital to recognize that hereditary information is a family possession rather than simply a personal one”. Yet, if genetic information is treated as family property, the traditional boundaries, definitions, and obligations in the healthcare professional - patient relationship would be extended to all the family members, leaving the healthcare

Corresponding author: Luciana Caenazzo,
Department of Environmental Medicine and Public Health,
Legal Medicine Unit,
University of Padua Via Falloppio, 50 35121 Padova, Italy
Phone: +390498272234, fax +390498272214,
e-mail: luciana.caenazzo@unipd.it