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## THE EXHORTATION OF RISK DISCOURSE AND THE COLLECTION OF AUTOLOGIC UMBILICAL CORD STEM CELLS

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### ABSTRACT

**Objective:** this article addresses risk discourse in parental testimonies found on websites of autologous biobanks that store umbilical cord stem cells for cryopreservation, as a cultural artifact.

**Method:** the discussion is grounded in the question: how does the rationality of risk and its biological pledge constitute parental statements published on websites that commercialize both the collecting and storage of stem cells from umbilical cord?

**Results:** the exhortation of risk discourse is approached, depicting how its prevention is constituted as a mobilizing element for the acquisition of this biotechnology, educating parents to adopt certain health practices related to biosecurity for the future.

**Conclusion:** the analyzed parental statements allowed the identification of biotechnology practices that drive and reposition families in relation to health care of children, to avoid risk.

**DESCRIPTORES:** Risk management. Technology assessment biomedical. Community health nursing.

## A EXORTAÇÃO DO DISCURSO DE RISCO E A COLETA AUTÓLOGA DE CÉLULAS-TRONCO DO CORDÃO UMBILICAL

### RESUMO

**Objetivo:** este artigo aborda os discursos de riscos presentes nas publicações dos depoimentos de pais e mães em *sites* de biobancos autólogos que armazenam células-tronco do cordão umbilical para criopreservação, tomados aqui enquanto artefato cultural.

**Método:** a discussão baseia-se na questão: como a racionalidade do risco e sua promessa de garantia biológica no futuro se constituem nos depoimentos dos pais publicados nos *sites* que comercializam a coleta e o armazenamento de células-tronco do cordão umbilical? A coleta de dados ocorreu entre março e dezembro de 2014.

**Resultados:** aborda-se a exortação do discurso de risco, apresentando-se de que modo a sua prevenção se constitui como elemento mobilizador para aquisição desta biotecnologia, educando pais e mães para a adoção de determinadas práticas de saúde vinculadas à segurança biológica para o futuro.

**Conclusão:** a partir da realização da análise do discurso dos pais e mães foi observado como as biotecnologias conformam práticas e repositionam as famílias, em relação aos cuidados de saúde dos filhos, com vistas a evitar riscos.

**DESCRIPTORIOS:** Gestão de riscos. Avaliação da tecnologia biomédica. Enfermagem em saúde comunitária.

# EL RIESGO EXHORTACIÓN DE EXPRESIÓN Y DE COLECCIÓN AUTÓLOGO DE CÉLULAS MADRE DE CORDÓN UMBILICAL

## RESUMEN

**Objetivo:** este artículo aborda los discursos de riesgo presentes en las publicaciones de los testimonios de padres y madres en *sites* de biobancos autólogos que almacenan célula madre del cordón umbilical para crio preservación, tomados mientras artefacto cultural.

**Método:** la discusión se basa en la cuestión: como la racionalidad de riesgo y su promesa de garantía biológica en el futuro se constituye en los testimonios de los países publicados en los *sites* que comercializan la colecta y el almacenamiento de célula madre del cordón umbilical.

**Resultados:** se aborda la exhortación del discurso de riesgo, presentando de qué modo su prevención se constituye como elemento movilizador para adquisición de esta biotecnología, educando padres y madres para la adopción de determinadas prácticas de salud vinculadas a la seguridad biológica para el futuro.

**Conclusion:** a partir de la realización del análisis del discurso de los padres y madres se observa como las biotecnologías conforman prácticas y reposicionan las familias en relación a los cuidados de salud de los hijos, con vistas a evitar riesgos.

**DESCRIPTORS:** Gestión de riesgos. Evaluación de la tecnología biomédica. Enfermería en salud comunitaria.

## INTRODUCTION

This paper, aims to address risk discourse present in publications regarding parental statements on autologous biobank websites that store umbilical cord stem cells for cryopreservation, is derived from the doctoral dissertation of one of the authors, and is part of the interface of Cultural Studies and the Pedagogy of Risk. From the theoretical contributions of these fields, we sought to understand how adherence to the biotechnology of collecting and storing autologous umbilical cord stem cell acts from the position of the subjects, fathers and mothers, regarding adoption of current practices which aim to prevent future risk.

The discussions on the empirical material, together with theoretical contributions - the molecularization of life and risks, had the pretension to problematize and to understand the recommendations and information related to the collecting and storage of umbilical cord stem cells, considered here as a set of educational practices that reposition, and parents assume responsibility for health care provided to their children and, especially, for risk control in order to guarantee future biological safety. The discourse published on the websites has been associated with educational practices that help with the production of new and different ways of caring for children, managing life and the future, and produce different meanings on issues involving biological safety regarding risks.

The statements presented in this paper exemplify the benefits of collecting and storing umbilical cord stem cells. Certainly, it could not be different, as such sites are conceptualized and produced with the purpose of publicizing and selling the service offered by the biobanks. However, from the statements analyzed, it is possible to highlight some repercussions on the subject, namely, the offer of

new biotechnologies that may help in health safety and the importance of investing in procedures, in this case, during pregnancy, aiming to guarantee opportunities of treatment for possible future illnesses of children. Moreover, it is possible to state that these understandings help produce new forms of knowledge and adherence to these practices that, despite being conducted today, deal with promises for the future, as occurred with organ transplantation, genetic research, selection of embryos for in vitro fertilization, and the use of some medications, for example.

In this sense, this theme is relevant for nursing, since its performance is implied in the different stages of this process. Biotechnologies are contemporary, biomedical technologies that seek not only to cure disease, but also to interfere in vital processes, involving social relationships that give new meaning ation about life and the optimization of the future. In this process, life becomes the target of technical interventions, that is, a bio(life)-techno(-technique)-logy(study).

Through genetic biotechnologies, it becomes possible to change certain genetic conditions, because the possibilities of technological intervention in life constitute knowledge about it. This knowledge is coupled with control strategies that use biotechnologies in order to maximize and improve characteristics that, until the mid-twentieth century were considered unattainable, such as the prevention of genetic diseases, the programming of compatible siblings for transplants, intervention in eye and hair color, among others. So, promises and prospects from the field of biotechnology are experienced, occupying a place of excellence and centrality, because from this area of knowledge it became possible that such promises were, if not conceived, at least materialized.<sup>2</sup>

Biotechnologies have been gaining an increasing space in the production of ways of thinking and relating to oneself, as well as a manner of developing health professionals, among them, nurses. It could be said that they also work as a form of government that controls the possibility of the finitude of life, since they make it an artifact that must be modified by technical intervention, by the imposition of beauty, health, and, in the end, by the possibility of manipulating the body and cells.<sup>2</sup> The storage of stem cells for autologous use, denominated by biobanks as “biological insurance”, would be a good example of future management and vitality.

## METHOD

This article is part of the interface between the fields of Cultural Studies and the Pedagogy of Risk.<sup>3</sup> <sup>4</sup> The empirical material, researched from March to December of 2014, are related to the publications in five sites – CordCell,<sup>5</sup> CordVida,<sup>6</sup> CCB - Brazil Cryogenia Center,<sup>7</sup> Hemocord,<sup>8</sup> CrioBanco<sup>9</sup> - autologous/private biobanks available on the Internet. The criterion for choosing these sites was the availability of a specific field of published parental statements. For the research, five sites were used, but for the discussion portion of this article, parts of them were used. It is assumed that this form of communication has participation in the modes of existence of fathers and mothers who participate in the collection and storage of umbilical cord stem cells.

The production of the data occurred from immersion in the statements found in the sites on what the fathers and mothers, biobank customers, thought about this biotechnology and how these discourses were transmitted, based on the ideas of risk prevention and the desires of a certain type of biological safety. In this sense, multiple accesses to each statement were identified and analyzed from the perspective of discourse analysis, in which the subject is understood as a product of the discourse, and the relationship between knowledge and power. This research is based on the theoretical perspective of Cultural Studies, considering a post-structuralist view of analysis, based on Foucaultian references.<sup>10-11</sup>

These empirical materials consisted of secondary data available on the open internet, so, submission to the Research Ethics Committee was not necessary. The study that gave rise to this article was consistent with the ethical principles of Resolution 466/12.

The statements analyzed were identified according to the availability of the biobanks on the open internet network, with the respective date of access.

## RESULTS AND DISCUSSION

### Who gives value to life, preserves the stem cells? - the exhortation of the discourse of risk

*We decided to have a child because we have faith in the future; we want a better world, especially without diseases or other unforeseen events. We know that we will have to take care of this baby with the greatest love in the world, but sometimes all that love does not stop something bad from happening. So, prevention is better, isn't it? So, we decided to collect umbilical cord blood from our third baby ... We decided to collect the stem cells from our daughter Laura as a guarantee to use all the possible tools in case of a future health problem. Obviously, we hope not to need it, but with that decision, we expect to have increased our range in a possible intervention ... If God gives us other blessings with other children, we will certainly do the same! (CordCell)<sup>5</sup>*

The title, as well as the parts of the text that initiate the section on results and discussions, explain how this discursive of risk pedagogies is also present in parental statements, and explicitly adopts current practices in the name of the desire to have greater “power” in a future prevention of risk.

In the statements presented in the biobank website publications, “many” and “multiple” risk factors circulate for challenging other fathers and mothers to become what they call “entrepreneurs” of their children’s risks. Becoming entrepreneurs of their children’s risks, parents become administrators not only of the present, in which they must take care of feeding, immunization, accident prevention, among other aspects, but primarily as future administrators, keeping cells for an eventuality, for unforeseen events, “for when love is not enough”. As we have seen in the presented statement, it is about *ensuring a better world, especially without disease or other unforeseen events.*

As identified, the decision of having a child adds practices related to the anticipation of risks, manifested by discourses of responsibility, to taking care of them well and forever. The anticipation of risks<sup>4</sup> turns everyone into a manager of a private sphere, each one being responsible for managing the hazards to which the family is exposed. By storing the stem cells of their children, parents act to safe-

guard the future of their children. It is understood that such practices reinforce the discourse that parents should plan and adopt measures in advance that may protect their children from risk.<sup>12</sup>

Thus, the discussions on the process of risk molecularization<sup>4</sup> constitute a useful conceptual tool for the problematizations of this research theme.

Genetic and epidemiological demarcations are fundamental for the development of a risk model, as they offer a high degree of effectiveness in determining the probability of becoming ill. The importance of this aspect lies in its relationship with conduct that leads to the search for protection against risks.<sup>4</sup> The storage of umbilical cord stem cells seems to be configured as a protective conduct of parents for their children, represented in the sociocultural field in which they are integrated.

In the case of the practice discussed here, the risk is not based on percentages, propensity, or epidemiological data. Parents that consume these biotechnologies are considered to be demonstrating that there is no "clinical" indication\*\*, epidemiological indication or genetic risk; they act in an effort to have one more chance, one more possibility, one more protection for their children in the future.

Such practices constitute the molecularization of risks, related to the emergence of a "new genetics", linked to the health area. Although there is no satisfactory degree of predictability, parents use technological advances as a means of justifying actions in the name of avoiding possible risk.<sup>13</sup>

The molecularization processes of life and risks, which seem to justify the storage of cells for future treatment of diseases, are considered to represent a particular way of understanding life, in which a set of mechanisms at the molecular level is recombined into new intervention practices, including treatments for diseases that are derived body components.

The analytical exercise indicates that the justifications for collecting and storing stem cells are mostly based on the belief in a technology that promises some "biological/molecular/cellular" safety for the future.

This leads individuals to self-administer in certain ways, but mainly to model their actions and behaviors using strategies that protect them from a greater contingency of risks.<sup>14</sup> By knowing the possibilities of using umbilical cord stem cells, it is expected, according to biobank website publications, that parents will be responsible and prevent risks, by self-managing and assuming responsibility

for the fate of their children.

Families elaborate their own justifications for adhering to certain conduct and Taking advantage of various technologies. The social and cultural development of the notion of risk, in this case, seems to assume a kind of exhortation to vigilance, which occurs by means of multiple instruments and procedures, in order to try to ensure the health of individuals.<sup>15</sup>

As for risk management, the statements presented on the websites help parents to learn how important it is to be able to care for their children's health in a committed and competent way. This seems to be more evident when the argument used is that even love may not protect children, although it is presented as an almost essential prerogative for all parents, whereas the cells can. This aspect can be observed in the following extract: *we know that we will have to take care of this baby with the greatest love in the world, but sometimes all this love does not prevent something bad from happening* (CordCell).<sup>5</sup> In the name of this love, an incessant search for something that can "protect" the child proceeds. If umbilical cord cells are a possibility, why not store them? *So, prevention is better, isn't it? That is why we decided to collect umbilical cord blood from our third baby* (CordCell).<sup>5</sup>

Articulated surveillance of rational risk management points to a permanent desire to manage life, to be safer, especially in the health area. Biotechnologies, even those that seem to have a strong aura of fiction, such as the multiple future possibilities of using stem cells, call on everyone to accept maximum levels of management of their lives, to avoid risky situations.<sup>4</sup>

The analyzed statements present the notion of risk under an aversive approach, based on information that disseminates perspectives of medical science, in terms of adopting attitudes related to health promotion. It is possible to say that the notion of risk that leads to the adoption of technology is also based on hybrid perspectives, which include ideas of control of "imaginary risk", based on the vulnerability/fragility present in the ways that parents see their children.<sup>4</sup> This imaginary risk, motivated by parental perceptions regarding vulnerability/fragility, can be understood from the statement related to the perspectives of anticipation of this risk. This was identified in the extract from the following statement: *preserving my children's stem cells was a way of telling him that I care about his future. Not that a disease or something is desirable, but rather, in life the*

*diseases appear without asking permission and without a certain date. The process of collecting the stem cells was quiet, painless and rapid. I chose that, because we cannot predict the future (CordCell).*<sup>5</sup>

Risks are always in the order of anticipation.<sup>16</sup> This is future management, the likelihood of an event occurring. This management takes place in two ways: from the adoption of preventive measures, such as immunization and use of protective equipment; and from compensatory measures, which are safe. The statements analyzed indicate that new technologies perform other modes of risk management, which are concomitantly developed with the emergence of new biotechnologies. In this way, people are identified as susceptible carriers, which, in turn, reconfigures the risks to which they are exposed.

The parents and biobank customers are positioned as consumers of health technologies. From access to information, they are able to compare and decide on the risks and costs of taking early steps to promote the health of their children. It is up to each one to assume the responsibility of adopting actions that guarantee a healthy and, preferably, risk-free life, in what has been configured as 21st century biopolitics.<sup>2</sup>

It can be said that the problematization of risk and its proliferation are directly linked to media diffusion of real statements, whose scientific status appears indisputable. The statements analyzed indicate that, to act responsibly, fathers and mothers should be informed about discoveries and know normative discourse that derives from scientific truths. In the first place, they must be open to expert advice, those who regulate modes of paternity and maternity, according to a hegemonic model. It is possible to say that the parents are positioned within the scope of generalized prevention, whose goal would be to reach the maximum of protection from risk.<sup>14</sup>

The media narratives about self-care emphasize the action of the present in the name of the future, in other words, a suggestion that acting right now means adding hope and years of life into the future. This can be understood from the statement about bioascets where the will to care for oneself is not in the service of freedom - it serves science. The attitudes of individuals towards themselves are at the service of prolonging and maximizing life.<sup>17</sup> The individual who cares for himself will know how to behave in relation to care for the other, especially if he takes risk discourse as a structuring element for organization of his actions. It is important to

emphasize that risk discourse is strongly dependent on the media; that is, when placed in the media, risk discourse can become an event with a global reach. Thus, they are highly mediatized, selective, variable and symbolic.<sup>18</sup>

Health care anticipatory behaviors, such as those described, are derived from health campaigns with publications addressed not to those who are ill or are likely to become ill, but to the maximum number of subjects - in the case of biobanks, to the maximum number of parents who can consume such technology. Campaigns such as those promoted by biobanks derive from the expansion of possibilities of mapping risks from the findings of new genetics, which lengthen the temporal distance of the diagnosis of possible diseases; in this way, subjects start to take care of themselves in advance.

This positioning to guide daily life using adherence to recommendations published in the media is based on a multiplicity of sources, whose offerings are many, as are the possibilities of choosing to which one will adhere. This seems to produce a kind of chronic health care, proposed from statements that indicate that it is never too early to adopt practices that expand the possibility of avoiding diseases.<sup>17</sup>

Taking care of health becomes a practice that should be initiated very early, preferably before birth. The subjects become early consumers of medical technologies, in the name of guaranteeing a future with fewer risks and, presumably, more health. In this sense, risk discourse can be seen as an important contemporary societal organizer.<sup>19</sup>

Many aspects of life, as already mentioned, are under the responsibility of each person in contemporary society. The resulting responses are instituted by a moral panic arising from a phobic reactivity to risk.<sup>4</sup> This manner of looking at risk from the perspective of anticipation, and as a corporate organizer, is mainly marked by personal responsibility as a fundamental element that will guide the adoption of individual actions and their consequences. The parental statements published on the websites show the permanent presence of discourse that proposes the practice of anticipating risks that could occur in the future, as in the extract below.

*How can you have the gift of being a father of a cute little one like this, and not do anything to secure his future? That thought made me preserve the stem cells of my son's umbilical cord seven years ago. At the time, little was known about it, and the doctors themselves only considered it for leukemia treatment. Today I am very happy to know that my baby is already protected from approximately 100 diseases (CordCell).*<sup>5</sup>

*I decided to preserve my son's stem cells thinking about his health. I do not regret anything! It is a process that is super easy and smooth. Nothing in the world can pay for the certainty of having done my best for my son's future! Whoever values life, preserves stem cells (CordCell).<sup>5</sup>*

*We never know what unpleasant surprises the future can bring, when talking about illness. We know that Maria will have a second chance if she needs this stem cell storage ... (CordCell).<sup>5</sup>*

The first extract argues that whatever is possible in the present must be done to guarantee the future. The new biotechnological discoveries are related to the expansion of possibilities for disease treatment, that is, increasing the possibilities of reducing the risks of becoming ill, and are described as elements for happiness. These parents seem to feel protected from some types of health-related risks, which reinforces the hegemonic discourse of biotechnology consumption, which is not always what it seems. As seen in the first statement, the decision for storing the cells was supported by the possibility of leukemia treatment. After seven years, new possibilities are being offered, which leaves this father satisfied with the decision made, because, as he says, there are now more than a hundred diseases that can be treated from that body substrate.

The second text extract relates the preservation of stem cells with the value attributed to life. According to the statement, those who value life preserve these cells. This example seems to indicate that controlling risk is a seemingly easy "action" to manage, at least for those who can consume this kind of molecular safety. The risk discourse uses the form of scientific knowledge and truth to be followed, subjecting subjects to certain consumptions, such as the autologous storage of umbilical cord stem cells.<sup>18</sup>

As demonstrated, commercial sites that conduct a marketing campaign for private biobanks are analyzed. In this context, the subject of consumption<sup>20</sup> is the envisioned individual, influenced by the consumption imperative that obtains pleasure and exercises power, finding meaning and practicing sociability from what was purchased. This subject has been increasingly understood from his individuality, which plays a key role in the development of consumer technologies. Thus, biobank advertisements can be seen as a cultural instance that offers places where the passions, hopes, and human anxieties of inpatient parents can be explored, by consuming products

that may protect their children from "unpleasant surprises" in the future.

When the parental statements are questioned, it is possible to observe that private biobanks, through their advertisements and constant investments in the dissemination of information, reiterate the transformation of umbilical cord blood as biological capital for the prevention of risk. It should be noted that this process of converting parts, cells, human molecules into biological capital is developed and produced by a network of agencies, involving scientific research, biotechnological development, and discoveries in the field of genetics, among others.<sup>20-21</sup> Biobanks attract consumers not only because they reinforce the prevention and promotion discourse present in the health field, but because they act on the passions and, especially, the hopes of a future without surprises, as described in the third text extract presented.

In contrast to extracts from parental statements published by private biobanks, the digital booklet<sup>22\*\*\*</sup> "*Knowing the umbilical and placental cord blood banks - Helping future parents to make a conscious decision*" warns that umbilical cord cells for autologous use cannot always be used. This alert mainly concerns cases of genetic diseases, including some types of leukemia, as the cord blood can carry the same genetic material and the same defects responsible for the disease manifested. In addition, there are rare reports of autologous cord blood transplantation worldwide. There are also no statistics on the use and effectiveness of these treatments. So far, as the booklet points out, a child's chance of needing its own stem cells is extremely low.

This study suggests that nursing professionals should problematize the biotechnological offerings that provide individuals with a range of possibilities, from the promise of biological safety for life. In addition, a wide field is indicated for new analytical investments that puts the promise of risk prevention from the consumption of technologies under suspicion, and points out new possibilities of nurses' performance.<sup>23</sup>

## CONCLUSION

The discussions in this paper indicate that the different news stories related to the biotechnological findings disclosed by the media, associated with risk prevention and directed at the children's health care, among them, collecting and storing umbilical cord stem cells, are part of the process of regulating

families. Currently, the family must fulfill its social obligations in order to maximize the physical and mental well-being of its children, as a privileged path to its own happiness, and biotechnologies are one of the possibilities to achieve this. In the analyzed data, it is noticed that when this ethic drives life, family members begin to evaluate and normalize their conduct, as fathers/mothers in the family, through a reference to standards that are created by experts and considered normal.

This mechanism, according to the discussions presented, drives the social field by means of an alliance between the power of expertise and the desires, hopes and fears of the parents and autonomous family, committed to improving their quality of life and the health of its members. The statements published on the websites allow us to consider that the storage of a child's cells provokes a series of cultural ramifications related to regulatory mechanisms of the families, which include the adoption of new parental positions in relation to the care of their children.

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