

The narrative of identity in the context of human assisted reproduction

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Background

Thousands of people were born through the medically assisted reproduction techniques. However, most do not know it. This information, which is closely related to identity, is not transmitted to them by those who have this duty, especially parents. The results of studies on the disclosure of the truth to their children indicate that most parents do not want to do it because they do not feel prepared for it, they do not have access to information or training on how to do it; others in no way intend to tell their children the truth; others have already done so and do not regret it. Most families report that they feel unprotected, helpless and afraid. They confess that they would feel more prepared if they had greater support from the Health professionals.

Methodology

This investigation aims to analyze the speeches of those who were born through the assisted reproduction techniques and who had access to this information in different ways, or through their parents; or through a conversation they overheard; or by carrying out genetic tests, among others. Identify their needs, combine the interests of the other medically assisted reproduction process stakeholders, such as parents and gamete donors, and reach, through a bioethical and legal approach, a resolution to be attended by health professionals to prepare parents for the importance of the identity narrative and the discourse to have with the children.

Results

The shared stories are based on a narrative of suffering, pain, confusion, revolt and disappointment. These narratives result from a complex plot that is based on the omission of essential information related to the identity of the descendants of Assisted Reproduction Techniques (ART), from their parents. Diverse stories were told to the descendants of ART, but none of them contained the truth about the genetic origin, the way they were generated and the gamete donor resource and identity. These people were led to believe that they were born in a natural way and that their parents were their genetic parents. They developed their personality on false pillars and thought they knew who they were. With the discovery of the truth in adulthood, these people saw their lives interrupted. From one moment to the next, without any warning, they learned that after all, they were not who they always thought they were and suddenly they entered a void and a deep ignorance of themselves. In the narratives, we understand the burning desire that the voice of the descendants of the gamete donation be heard, that the silences are broken with information, with truth, with responsibility, with words that care and bring them closer.

Narrative

Kelly

«When I was 35 years old, nine years ago, my dad died of cancer. A few days later my mom told my sister and I that we had been conceived using donor insemination. She said, 'Your father may not have been your real father'. Initially my reaction was to feel greatly relieved. This new information explained so many unanswered questions I had; resolved a fog of confusion I had. As time went on, some of the realities of this situation sank in. I became very depressed for a while. I wasn't the person I thought I was. And my parents, the people I should be able to trust the most in life, had lied to me for 35 years about something so vital: about who I was. Rather than grieving my dad's death, I was incredibly angry at him. My mom said that when we (my sister and I) were teenagers, she had wanted to tell us about the DI, but my dad 'made her promise' not to tell us. I am glad to know the truth, the truth is always better, but her timing was horrible. I was also upset that now I wasn't able to talk to my dad about it. As a human being, I should have a right to the truth about my own identity and history. I would like to be able to sit down and chat with [my donor], but I have accepted that most donors, especially from that time period, don't want any type of relationship. I should be able to know who all of my blood relatives are, including the donor's family members and all of my half-siblings through his sperm donations, so that I wouldn't marry my half-brother, and so that my children won't marry their first cousins. It was so important to my parents for me to fit into the family because they were hiding my genetic background from the whole world: from family, from friends, from neighbours, from the school, from my doctor. They spent my whole time with them trying to squash me to fit into the characteristics of the family, to mould me in their image. Unfortunately, I just didn't fit into their mould. It was so painful to find out my dad had lied to me our whole life together about our true relationship, and that he felt it was none of my business. I had to redevelop my sense of identity, because I wasn't the person I thought I was.»

(Kirkman, 2003)

Conclusions

Parents are primarily responsible for revealing to their children all the elements and information that build and polish their identity, in particular, those that are related to their genetic origin. With the birth of the child awaited by the beneficiaries of ART, a set of rights is also born that must be safeguarded and respected, namely, the right to knowledge of genetic origins. This right allows anyone to know how they were generated and by whom they were generated, so that they have full knowledge of their true personal identity.

Narrative Medicine aims to develop the narrative skills of health professionals, that is, the ability to recognize, absorb, interpret and act taking into account the stories and difficulties of others. In the field of reproductive medicine, narrative skills do not end in recognizing the suffering of people with fertility problems, in interpreting the history of the disease and in sensitizing health professionals in relation to the vulnerability of those they care for. Narrative medicine extends to those who have not been born yet. Doctors must have the competence to create a bridge between their patients and the children who will be born as a result of ART treatments. If, at first, care and the relationship is centered on the patient; in a second step, the interests, rights and vulnerability of those who have not yet been born are called to dialogue.

Health professionals, specialists in reproductive medicine, must attend and allow themselves to be invaded by the truth, by the shout for help, by the anguishes, by the pain and incomprehension that emerge from these narratives. They must be made aware of the narratives of those who are born as a result of ART treatments and who do not have access to their biological truth. Throughout the therapeutic process, health professionals who accompany the beneficiaries must make them aware of the duty to reveal the biological truth to their children. This multidisciplinary follow-up must continue even after the birth of the child so that the beneficiaries feel safe and confident in transmitting the truth to their children. This disclosure must be made at the right time, at the right age, with the appropriate terms and words adapted to the children's ability to understand and adjusted over time, according to the child's development. Children must also be accompanied by this highly qualified team, capable of listening and reflecting on the narratives, helping to deal with difficulties, with possible loss of identity, with suffering, with confusion or other less positive feelings about beneficiaries and themselves.

References

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