Privacy vs. national security: stem cell research and its impact on medicine essa...

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Human embryo stem cell research is an emerging field in medical science which has raised serious ethical issues. It is still a matter of debate whether or not this technique should be employed for the research purpose and what would be the end result of the embryo. Since the research process has advanced a lot, the prime focus at the present time is not to decide whether or not it should be done but to determine ways to maintain the privacy.

The government looked into the matter of human stem cell research because those derived from animal sources had potential risk for rejection by the immune system of humans due to different antigens on them which are recognized as foreign by the human body. The government proposed a long list of prerequisites for carrying out the research process which strongly overlooked the privacy issues (Lo et al. 5).

These measures by the government includes detailed consent in written form by those who are donating gametes, that is ova or sperm, cheap rates at which the gametes can be made available and proper testing of the donors along with their details in written form. These rules strongly targeted privacy, and therefore efforts were made to find solutions and to protect privacy.

The first step in this direction is to save guard the privacy of the donors who enroll in the initial trials that helps to decide the suitability of that particular clinical study. It can be done by using minimum doses of the medicines that do not significantly affect the donor’s life, so the purpose is to assess the safety of the procedure rather than assessing the effect of the procedure.

It is very important to protect the privacy by preventing overt or obvious effects on the donor, and this is ensured by the reduced doses and down-

regulated drug or intervention. While performing the research, there is an increased chance of the donor being a source of any disease transmission or any hereditary condition.

This can be a drawback because the end product of the research is expected to be free of such flaws. This was the prime reason that strict donor screening was introduced when blood or organs were donated in order to pick any blood borne or hereditary condition and to prevent it from being transmitted to the recipient and required thorough information of the donor. A similar rule was applied to the stem cell research by the government. The need for privacy in this regards was considered due to the fact that there might be a long duration of time between the donation and the eventual transplantation of the end product that is obtained through stem cell cloning.

This long time period might make the donor material likely to become exposed to infections that show their clinical manifestations quite late, remaining latent for years and years. Secondly certain hereditary conditions also manifest years later at a particular stage in life, such as cancer and the donor might be unaware of its existence when he made the donation.

There might also be the risk of that the recipient might develop any illness secondary to the use of immunosuppressive medicines that are routinely prescribed after organ transplant and which can be falsely claimed to be due to problems from the donor. Thus, the above mentioned reasons not only justify but also make it an obligation to ensure privacy of the donor because the transmission of a particular medical condition might be just by chance, the donor being totally unaware of it and also due to fact that in case such

conditions are disclosed it might be a source of humiliation for the donor. There would be a risk of social embarrassment for the donor who might refrain from further cooperation with the research team and develop an attitude of denial. The information of the donors also needs to be protected from being leaked out through paramedical staff, files being stolen from research centers or directly from the computers by hackers. In order to keep donor’s privacy as a top consideration, strict measures can be adopted that include a vigilant check on the paramedical personnel and cautious approach adopted while appointing them by thorough personal evaluation and background check.

Furthermore a safe place should be allocated where the files and data of the donor is stored that does not have free access and that can only be viewed by a high ranking official and those researches that he allows. The government should also issue some legal document that protects the privacy of the donors.

There are also a few other sectors in such researches where there is a need for the privacy of the donor be maintained and correct information provided to the donor as well. This mainly occurs in initial clinical trials that check whether a particular therapeutic agent, genetically engineered through stem cell or otherwise will benefit or not.

It involves a low dose assessment of the effect of a particular agent on the study group that might be diseased (case) or healthy (control). Here caution is required by giving full information to the individuals in the form of well explained consent forms that explain that the purpose of such trials is not to cure the condition because sub-therapeutic drug levels are being used, but

its main purpose is to evaluate the effectiveness of the drug which can be further tested before being marketed.

This is very important because the individuals who enroll in such programs are partially aware of the reality and expect to be cure whereas they may or may not receive much clinical benefit and may develop worsening of the condition. This was seen when dopaminergic neurons from the fetus were transplanted to people with Parkinson’s disease; there was severe worsening of the symptoms (Lovell-Badge 5).

Thus, it is very important for the researchers not to keep the individuals on whom clinical trials are being conducted in the dark by a subtle way of informing them about the purpose of such trials. This is important in order to protect the privacy of the people by allowing them to decide whether or not to enroll in such programs and risk their information being given to the researchers when they are unlikely to benefit from it clinically and also to address the ethical issues that arise from the use of stem cell as research material with different individual beliefs regarding the concept of life. Furthermore, it also makes it a transparent system whereby the purpose is made obvious, but the privacy is maintained.

Privacy is a very sensitive subject, and the need to protect privacy is of utmost importance. Although the government has its own laws, that are also made to benefit people, this concept of privacy has more social and ethical implications (Prainsack 2). Stem cell research is an evolving and rapidly progressing field of medical science where the role of maintaining privacy of the donors and individuals on which the research is being done is very

important in order to continue the research without a breech in privacy because it is an effort by the people, for the people.

Works Cited

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