Short Communication

Parental Psychological Trauma and Destroying the Records of the Deceased : Implications for Genetic Counseling and Management

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Genetic test reports are for lifetime and treatments available are not radical. In such cases substantial energy and resources of the parents are invested in laboratory diagnosis as the Genetic Tests are costly. If a genetic abnormality is found in a baby, there is always risk for the recurrence in subsequent pregnancies and also potential risk for the close blood relatives. Birth of a genetically abnormal child is always a Shock to the parents and if there is sudden demise of the baby the couple can experience a tremendous Shock and Depression. The Shock of demise is so severe that some families destroy the belongings of the deceased in order to overcome the grief. This destroying of medical record brings limitation in genetic counseling if next pregnancy is planned. The importance of preserving the documents should be stressed on and implications should be discussed with the parents.

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Sudden and untimely death of the child can be shocking for the parents. Especially if the case is with a Genetic Disorder. In such cases substantial energy and resources of the parents are invested in laboratory diagnosis as the Genetic Tests are costly. Free Government facilities are not available especially in low and middle income countries and even if available are not always accessible by all. So, mostly genetic testings need to be done in private laboratories at higher costs. The upbringing of such babies is not easy for the parents. Some of the common genetic conditions like Down syndrome can affect two generations as such babies can survive up to 50-60 years. In such families one of the parents may have to dedicate his/her life time for upbringing of such babies. Additionally, even the siblings of the affected baby may have to suffer for upbringing of such babies. Genetic Test reports are for lifetime and treatments available are not radical. Also the reports are not only applicable to the patients but for all the family members hence, they are always important for overall management of the entire family. If a genetic abnormality is found in a baby, there is always risk for the recurrence in subsequent pregnancies and also potential risk for the close blood relatives. Since there are very limited treatment modalities available and considering the associated social stigma, birth of an abnormal child is always a Shock to the parents. While coping with the circumstances, if there is sudden demise of the baby the couple can experience a tremendous Shock and Depression[1,2,3]. The incidence of the same is commonly reported during Genetic Counseling sessions among the primary care givers due to the death of the child. There is a feeling of major loss and despair and sometimes they may need psychosocial interventions to overcome the situation[4]. It is common finding in the counseling sessions that there is always a guilty feeling in the parents that they have passed the abnormal gene or variants to the baby and because of them the baby has to suffer. It takes months for them to come out of this loss[1,4,5]. After going through this phase of psychological, social and financial sufferings, the Shock of demise is so severe that some families destroy the belongings of the deceased in order to overcome the grief. These belongings may include used clothes or utensils, photographs of the dead person and sometimes even the clinical documents of the cases including the test reports having immense important genetic information. These practices display un-acceptance of the present situation and such customs are kind of defence mechanisms to deal with

Editor's Comment :

- Preserving Genetic Test reports are very important.
- The importance of preserving all clinical reports should be explained to the patient/parents during counseling.
- Genetic tests are costly and once in life time test so if reports are stored repeat testing can be avoided.
- Unavailability of records of the deceased brings limitation in counseling.

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the situation. It can take even long time for the couple to come out of this condition[1,4,5]. Also it becomes very important to give support to the couple experiencing the loss to come to normal[6].

Importance of Clinical Records :

Taking history of the presented case is inevitable part of Genetic Counseling. Documents or records of the deceased are a very important piece evidence of manifestation of disease, in absence of which obtaining complete history becomes difficult. Information given orally if supported by proper documentation only then can prove to be useful in designing the guidelines for further management especially for offering prenatal Genetic Testing. There can also be certain lapses on part of family members to report the diagnosis of the patient. In such cases it becomes difficult for the genetic counsellor to estimate the severity of disease level and predict the risk of recurrence.

Economic Implications :

Genetic Tests are comparatively very expensive. They are once in a life time investigation and hence repeat testing is not advised. However, if the records are not preserved, repeating the genetic tests for diagnosis is impossible as the person is diseased, in some cases retrieving the lab reports can be possible if the lab is accredited and is responsive. Also repeating the tests for relatives can be expensive. Especially if mother of the deceased is in advance maternal age or wants to go for ART procedures, repeating the tests can be time consuming as the success of ART procedures also matters.

CONCLUSION

In conclusion, while sharing the reports during genetic counseling, parents/siblings/ other should be explained the importance of preserving all clinical reports. At first counseling sessions there can be information overload and tendency to forget is common, in subsequent follow up these points should be reiterated. Importance of preserving the documents should be stressed on and implications should be discussed. If possible this can be mentioned on the reports as well in short. There is an acute need of having a protocol in place to support these parents. This support should also include the proper storage of important reports of the demised babies as these can be very crucial for offering Genetic Counseling to the couple in all future pregnancies. The literature available is very limited and enough studies needs to be done to have a standard protocol for dealing such cases.

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