Genetic counselors’ experiences with presenting adoption after a prenatally diagnosed fetal abnormality

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Approximately 2-4% of clients who have prenatal diagnostic testing will receive an abnormal result. Afterwards, healthcare professionals have the opportunity to present various pregnancy options, including parenting the child, terminating the pregnancy or placing the child for adoption. The first two options are the most widely chosen by clients. It can be presumed that these options are fairly well understood by genetic counselors and most feel comfortable with the available resources regarding these topics. Current literature indicates that the third option, adoption, is not always discussed in cases where it may be appropriate and, when it is discussed, healthcare professionals do not always present the information in a non-biased manner. Clients should be informed of all available options and, should they choose to pursue adoption, the appropriate information should be provided. The aim of this study was to explore why and when adoption is offered. In total, 54/300 (18%) of prenatal genetic counselors from the NSGC prenatal SIG participated in this study. The results indicated that the option of adoption was discussed frequently by 35%, occasionally by 39%, rarely by 24%, and never by 2% of counselors surveyed. The diagnosis was the most important factor mentioned (86%) when deciding to present adoption. The respondents were most likely to offer adoption for a diagnosis of Down syndrome (43%) and least likely to offer it for a diagnosis of trisomy 18 and 13 (4%). The clients’ decision status was the most frequently stated (83%) reason for not offering adoption. This study indicated that while each individual case is different, in general, adoption is offered most frequently for conditions that are non-lethal though chronic and include significant disability. Additional resources are needed for genetic counselors to present adoption fully and provide follow-up resources to clients who are interested in pursuing adoption.