

Mothers' Experiences of Continuing Their Pregnancy after Prenatally Receiving a Diagnosis of Down Syndrome

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Abstract : Within the last few decades, major advances in the field of prenatal testing have transpired yet little research regarding the experiences of mothers who chose to continue their pregnancies after prenatally receiving a diagnosis of Down Syndrome (DS) has been undertaken. Using social constructionism and interpretive description, this retrospective research study explores this topic from the point of view of the mothers involved and provides insight as to how the experience could be improved. Using purposive sampling, 23 mothers were recruited from British Columbia (n=11) and Ontario (n=12) in Canada. Data retrieved through semi-structured in-depth interviews were analyzed using inductive, constant comparative analysis, the major analytical techniques of interpretive description. Four primary phases emerged from the data analysis 1) healthcare professional-mothers communications, 2) initial emotional response, 3) subsequent decision-making and 4) an adjustment and reorganization of lifestyle to the preparation for the birth of the child. This study validates the individualized and contextualized nature of mothers' decisions as influenced by multiple factors, with moral values/spiritual beliefs being significant. The mothers' ability to cope was affected by the information communicated to them about their unborn baby's diagnosis and the manner in which that information was delivered to them. Mothers used emotional coping strategies, dependent upon support from partners, family, and friends, as well as from other families who have children with DS. Additionally, they employed practical coping strategies, such as engaging in healthcare planning, seeking relevant information, and reimagining and reorganizing their lifestyle. Over time many families gained a sense of control over their situation and readjusted to the preparation for the birth of the child. Many mothers expressed the importance of maintaining positivity and hopefulness with respect to positive outcomes and opportunities for their children. The comprehensive information generated through this study will also provide healthcare professionals with relevant information to assist them in understanding the informational and emotional needs of these mothers. This should lead to an improvement in their practice and enhance their ability to intervene appropriately and effectively, better offering improved support to parents dealing with a diagnosis of DS for their child.

Keywords : continuing affected pregnancy, decision making, disability, down syndrome, eugenic social attitudes, inequalities, life change events, prenatal care, prenatal testing, qualitative research, social change, social justice

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