

Nonfinite Grief:

Reasons Doctors and Families Should Discuss SUDEP and Other Sensitive Subjects

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RATIONALE:

Dravet syndrome is a life-threatening epilepsy syndrome with onset in infancy and severe consequences for the development and general health of the patient. The mortality rate is described as very high (Roger, Bureau, Dravet et al). Sudden Unexpected Death in Epilepsy (SUDEP) is a recognized syndrome in which a person with epilepsy dies suddenly with no explanation. In patients with Dravet syndrome the incidence of SUDEP appears higher than in other forms of epilepsy, yet doctors rarely discuss the possibility of SUDEP with their patients' families. Parents of children with Dravet syndrome have expressed concern about this and the desire for open discussion between doctors and families. Nonfinite grief theory as proposed by Bruce and Schultz suggests some good reasons for doctors to talk openly about SUDEP and other difficult subjects with these families. This model suggest that, as opposed to the traditional linear model for processing grief, where the goals are resolution and closure, nonfinite grief is cyclical with goals of adaptation and resilience. In order to process nonfinite grief, significant reality testing is required. A primary task of nonfinite grief is to learn coping skills that will help the family manage the stress of living with unremitting threats to a loved one.

METHODS:

The IDEA League (International Dravet syndrome Epilepsy Action League) is an organization of parents and professionals promoting improved awareness and understanding of Dravet syndrome. The IDEA League sponsors an online Family Forum, a support group for families of patients with Dravet syndrome. Six hundred and eight of these children are currently represented on the forum. Parents on the forum were invited to take a survey regarding their experiences of grief in relation to their child's Dravet syndrome to see if Bruce and Schultz's model is "a good fit." The survey took place from September 26 through October 1, 2009 and parents of 57 children with Dravet syndrome chose to participate.

RESULTS:

Of the parents who responded to the survey, 86% of the respondents acknowledged experiencing grief regarding their child's condition. Accurate information was seen as critical. Forty-nine percent of survey respondents reported receiving an accurate early diagnosis and felt that this was beneficial to the family's process of adaptation. Thirty-two percent reported receiving misdiagnoses or a delayed diagnosis and felt that this was detrimental to the family's process of adaptation. Fifty-eight percent of respondents reported that uncertainty regarding diagnosis and/or prognosis increases anxiety, while information helps them to adapt. Eighty-four percent of respondents report that it is helpful when the doctor provides realistic information, even when it is hard to hear. Two respondents preferred the doctor wait for them to ask the difficult questions when they were ready to hear the answer. Eighty-six percent of survey respondents want their child's doctor to help them be educated so they can participate in decisions toward balancing risk management for their child and quality of life for the child and their family.

Sixty-eight percent of survey participants say it is helpful to have their grief recognized and acknowledged. Referrals for support are important, as 89% of survey participants report that it is helpful to have support for learning to manage ongoing stress of caring for their affected child, 74% of participating parents report that it is helpful to have support for learning to replace original dreams with new ones, and 88% report that it is helpful to recognize how this experience has changed them.

Finally, it is important to preserve some sense of optimism. Eighty-four percent of survey respondents report that it is helpful to maintain reasonable hopes for their child's outcome and quality of life that have a foundation in reality. Eighty-six percent of parents report that they feel more optimistic and proactive when they have opportunities to participate in research.

Traditional Grief Model		Nonfinite Grief Model
Loss of a life/loved one	Loss	Recurring loss of identity and dreams
Learning to live without a loved one	Task	Learning to live with unremitting threat(s) to a loved one (e.g. SUDEP)
Linear with stages	Process	Cyclical with characteristic cycles
Resolution and Closure	Goal	Adaptation and Resilience

CONCLUSIONS: Most parents of children with Dravet syndrome have expressed that they feel it is important for their children's doctors to communicate openly with them about the difficult consequences of this disorder, including the high mortality rate and possibility for SUDEP. Without all the information, they feel they cannot make good decisions regarding the balance of risk reduction and quality of life—they cannot find their "new normal." Having a foundation in reality is key to the successful management of stress and grief that is necessary for adaptation and resilience.

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