

Poster presentation

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Tragic as a boundary experience by parents of a child with spina bifida

Marizjenne van den Heuvel*, Hans Schilderman and Hans van der Ven

Address: Faculty of Theology, Radboud University Nijmegen, Erasmusplein 1, PO Box 9104, 6500 HD NIJMEGEN

Email: Marizjenne van den Heuvel* - m.v.d.heuvel@theo.ru.nl

* Corresponding author

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Background

This study is part of the multidisciplinary research program "Prognosis of Spina Bifida" of the Radboud University Nijmegen. In the framework of this program both a prospective and a retrospective study on children with different types of spina bifida and their parents has been conducted; the disciplines involved were child neurology, neuropsychology, child & family studies and empirical theology. The empirical theological part of this program investigates the moral and religious orientations of parents of a child with spina bifida while confronted with the diagnosis and ongoing difficulties during childhood.

Materials and methods

This presentation will focus on 'boundary experiences', in particular the specific boundary experience of tragic. Boundary experiences can be regarded as confrontations with the contingency of human existence. These experiences fundamentally call into question the meaning of life. In the empirical theological project the four following boundary experiences were studied on the basis of theological conceptualisation and are subsequently studied empirically: tragic, suffering, guilt, and death. This presentation will focus on the boundary experience of tragic which refers to the experience of a tension between an '*I should*' and an '*I can't*'. The following questions will be raised: 1. Which attitudes towards tragic are present among the parents of a child with spina bifida? 2. Is there a difference in support of these attitudes when some neurological and neuropsychological characteristics are taken into account?

Results

With regard to the first question three attitudes (on the basis of factor analysis) towards the experience of tragic were found among parents (n = 103) of a child with spina bifida. Hereby a distinction is made between religious and non-religious parents. The average score at a 5-points-scale (1 = 'very weak', 5 = 'very strong') of the three attitudes indicate that the parents are uncertain about the model of physical tragic, and disagree with the models of personal and religious tragic. Preliminary results with regard to the second question cannot be given yet, because of the fact that the analysis is still well under way.