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TRAGIC EXPERIENCE OF PARENTS WITH CHILDREN SUFFERING FROM SPINA BIFIDA

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Abstract

This article deals with the tragic experience of parents with young patients suffering from spina bifida. Spina bifida is a congenital malformation of the nervous system causing neurological, urological and orthopaedic defects, as well as possible mental retardation. Since only limited prognoses of the child's mental and physical development can be given at birth, parents are continually confronted with their child's limitations as they manifest themselves in both the first and each successive phase of life. These confrontations usually give rise to feelings of anxiety, helplessness and insecurity, because people come up against their own limits. The experience can be regarded as tragic. With the aid of a measuring instrument for tragic experience devised by Scherer-Rath (2001) we distinguish between three dimensions: a physical, a personal and a religious dimension. We examine to what extent parents of children with spina bifida have tragic experiences and in how far these vary with different neurological and neuropsychological symptoms, and with demographic, worldview-related and ecclesiastic characteristics. Our findings show that among mothers physical tragic experience varies with the severity of their child's spina bifida inasmuch as it concerns the functional lesion level. It also appears that both mothers' and fathers' religious tragic experience varies with worldview-related saliency, church membership and church attendance.

Key Words: tragic experiences, spina bifida, neurology, neuropsychology, worldview, church

1 INTRODUCTION

This article focuses on the tragic experience of parents whose children suffer from spina bifida. Spina bifida assumes different forms, from mild to severe. We expect their tragic experience to vary according to the gravity of the child's medical disorder, including the neurological and neuropsychological characteristics. We also expect such experience to vary with parents' demographic, worldview-related and ecclesiastic characteristics. The following questions were researched:

1. To what extent do parents of young spina bifida patients have tragic experiences?
2. To what extent do parents' tragic experiences vary with the patients' neurological and neuropsychological characteristics?

3. To what extent do parents' tragic experiences vary with their demographic, worldview-related and ecclesiastic characteristics?

2 TRAGIC EXPERIENCE

In the literature one can identify two traditions relating to tragic experience: the one pertains to tragic experience as chance, the other to tragic experience as fate. The former is an ontological tradition that can be traced back to Aristotle, who makes a distinction between actuality and possibility in everything that exists, in association with the concepts of necessary and not necessary. The possible is neither actual nor necessary (Van der Ven 1991, 168-171; Vermeer, 1999, 82-83). In this framework he describes chance as something that is possible, or at any rate not impossible, and not necessary (De Mul, 1994, 5). The second tradition is phenomenological and is represented by Guardini (1950). This approach centres on the necessity of an event or situation, in the sense that something which in the given circumstances cannot be other than it actually is, is necessary. There is an order in life and events that makes one realise that a situation or event must be what it is (Guardini 1950, 160ff.).

On the basis of this approach to tragic experience we can describe certain features of tragic experience, focusing on the situation of parents of children with spina bifida. The first is that the experience befalling the person strikes him or her as one of enormous sorrow, whether it is seen as (non-necessary) chance or (necessary) fate. This applies to parents of children with spina bifida: they are overcome by great sorrow. The second feature is that something existential is involved: one or more of the person's existential goals is threatened. In the case of parents of children with spina bifida it is the life of their child, which has existential significance for them. In addition their own lives and goals are at issue. The third and last feature relates to the second, inasmuch as they feel they must fight for what they value, the tragic experience being that it is beyond their power to do so. We find this same polarity between 'must' and 'cannot' in parents of children with spina bifida. They were unable to prevent their child's affliction and they are unable, or only partly able, to mitigate it.

These three features combine in a feeling of helplessness to undo the evil that befell the person or persons, in this case the parents, either by chance or by fate. They cannot or can barely grasp it (cognitively), they cannot or can barely endure it (emotionally), and they cannot, or can only with difficulty and special effort, cope with it (operationally). In tragic experiences the dominant feeling is helplessness.

3 DIMENSIONS OF TRAGIC EXPERIENCE

Tragic experience can be subdivided into the time in which they happen and the space in which they occur. As far as time is concerned we look at two timelines: a retrospective and a prospective timeline. Space is classified into immanent and transcendent space (Scherer-Rath, 2001).

Tragic experience along the retrospective temporal line relates to past experience that was perceived as either chance or fate and in which the dominant feeling was one of helplessness. One cannot turn back the clock, the situation is irreversible. What happened, happened; what was done cannot be undone. It is characterised by inability to influence the past, to undo, correct, ameliorate, remedy mistakes. All this applies to parents of children with spina bifida. When they look at the past they stand empty-handed, hands and arms helplessly outstretched, perhaps thrown up to high heaven. However devoted they may be to their child, they are powerless to control the past – were powerless at that time too, for that matter.

Tragic experience along the prospective temporal line pertains to the future that fills the parties involved with a sense of helplessness and impotence. They may have expectations, but time alone can tell whether they will be realised. They can make plans, but their feasibility is fundamentally uncertain. They may have hopes, but they have a sneaking fear that these will prove to be vain and that life may be an illusion. The future, like the past, exceeds human knowledge and capabilities. This tragic insight also occurs among parents of children with spina bifida. They do what they can to make life tolerable for their child and themselves; they look ahead prudently so as to take adequate precautions for the immediate future; but what the distant future holds is and remains enigmatic.

The temporal line of past and future permeate the space, both immanent and transcendent, in which the tragic experience happens. Immanent space has three dimensions: a physical, an intrapersonal and an interpersonal dimension.

The physical dimension of tragic experience is dominated by a sense of helplessness when one experiences one's own body as alien, even alienating. It is no longer experienced as a home in which one feels at ease with oneself, a companion on one's journey through life, a trusted friend. It is experienced as something separate from oneself, a bodily object (*corps object*), instead of a corporeal subject (*corps subject*) (Merleau Ponty, 1945). Such physical tragic experience also occurs among parents of children with spina bifida. Despite all the love and affection they have for their child, it sometimes strikes them involuntarily that they look at their child as a physically

alien being. Does the child belong in its own body, does it belong with them? They may also ask these questions about themselves, for tragic experience can play tricks on the parents' attitudes to their own bodies: how do they perceive their own bodies, from which the child was born? These questions are exacerbated when they are overcome by their child's suffering, medical interventions that have to be made, clarification of the obscure motives involved, the complexity of decisions that have to be made, the results and implications of these for the rest of their lives. These stressful experiences can give rise to physical ailments like headache, poor concentration, stomach ailments, insomnia, chronic lassitude and the like. Not only in the early phase but also as the child, and hence the parents, grow older they may struggle with physical ailments, for instance in situations where the child is not mobile and has to be carried everywhere, nappies have to be changed or catheters inserted, it has to be lifted in and out of the car.

The same experience of helplessness may arise in the intrapersonal domain. This concerns the individuals' relation with themselves, the existential drive to realise their own wishes, desires, hopes and ambitions and the impossibility that confronts them each time. They feel they have no influence over who they are, their own (excessively high) aspirations, their inadequate talents and abilities, and thus over their entire lives. Parents of children with spina bifida also have this experience. They imagined quite a different kind of life for themselves, wished for something very different. The single event, whether chance or fate, that has permanently marked their lives compels them to look at life anew and organise it very differently.

The interpersonal dimension is likewise marked by the experience of tragic helplessness. Usually it involves an incident that compels two or more people to reappraise their relationship, rearrange their dealings with each other, review their mutual expectations, readjust the help and support they have come to expect of each other. There is also a gnawing feeling of sympathy when one watches someone struggling and one is helpless to ease their suffering. This applies to parents of children with spina bifida as well: it is painful to see their child suffering and be unable to help. But the sense of helplessness may go further. They could be disappointed when they do not receive the support they expected from their partners, family or friends, or when others handle the situation in totally different ways that strain relations.

Tragic experience is rooted in transcendental space, at any rate from a phenomenological perspective, in the sense of the experience of chance or fate described above, when people feel that an event descends on them as it were from outside or from above. The grief and pain it causes demands,

so to speak, an address one can turn to so as to articulate one's feelings of impotence and helplessness. But chance is blind and fate is deaf. Religious people, however, have a transcendent address: the divine, God. They can turn to him and find strength and comfort. But not only that, and perhaps not primarily. They can also turn to God to express their disillusionment, sorrow and helplessness, bring their laments to him, possibly accuse him of the baffling, cruel whims in his creation. When that happens transcendent experience becomes religious experience. It also happens to parents of children with spina bifida. We know that bereaved people sometimes express a sense of God's absence, which they articulate in the form of a lament or an accusation directed against him (Zuidgeest 2001).

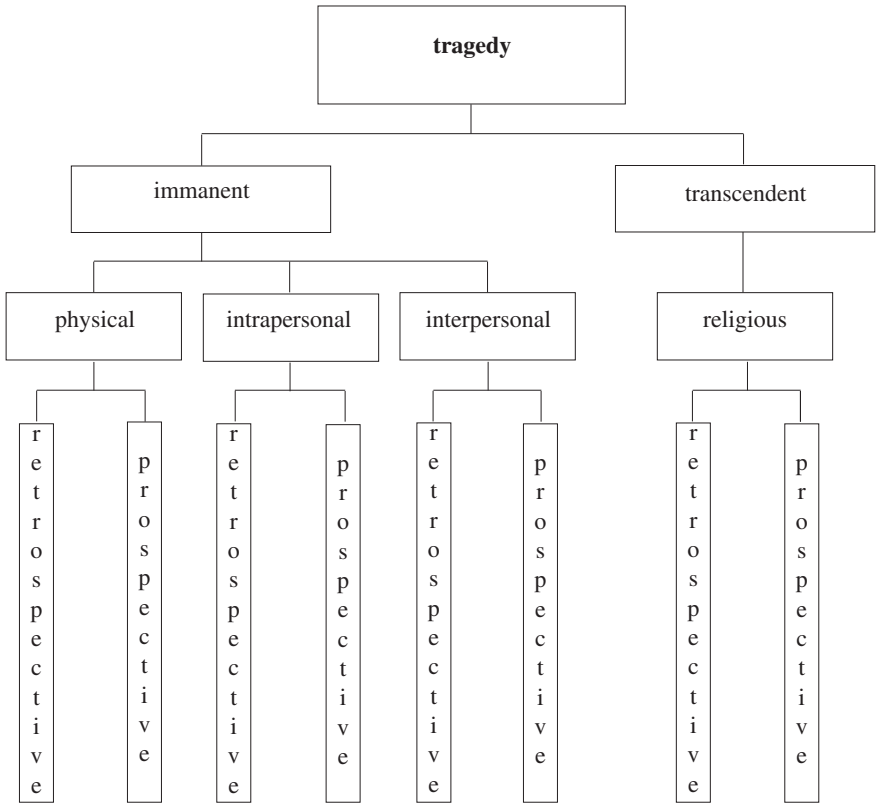
The various dimensions described above result in a concept of tragic experience comprising eight forms of experiencing tragic helplessness. These are produced by the distinction between immanent and transcendent space in tragic experience. Immanent tragic experience has three dimensions: physical, intrapersonal and interpersonal. The transcendent dimension is specified in relation to these. In each dimension there is a retrospective line referring to the past and a prospective line referring to the future (figure 1).

This conceptual model of the tragic experience of helplessness is the premise for answering the questions we posed at the outset: To what extent do parents of young spina bifida patients have tragic experiences? To what extent do parents' tragic experiences vary with the patients' neurological and neuropsychological symptoms? To what extent do parents' tragic experiences vary with their demographic, worldview-related and ecclesiastic characteristics?

4 MATERIAL AND METHODS

Research population

The research population in this study comprises two groups. The first consists of 46 young spina bifida patients whose neurological and neuropsychological particulars are known to the Radboud University Nijmegen Medical Centre. The second group consists of the parents of these 46 children whose demographic, worldview-related and ecclesiastic characteristics are known. The group comprises 44 mothers and 38 fathers. The data were collected between December 2002 and March 2004.

Figure 1. *Tragic experience from a theoretical perspective*

Measuring instrument

To test the conceptual model of tragic experiences (see figure 1) empirically among parents of children with spina bifida we used a measuring instrument for tragic experience developed by Scherer-Rath (2001) in his study of would-be suicides. For each of the eight aspects of tragic experience (physical, intrapersonal, interpersonal, religious and the retrospective/prospective distinction within each dimension) the instrument contains three items on a 5-point scale (1 = 'very weak', 5 = 'very strong'), hence 24 items altogether. We cite an example relating to each aspect. The items were introduced as follows:

"People usually want to achieve certain things in life. At the same time they may be overcome by a helpless feeling of being unable to achieve them.

I want to ask you to what extent you overcome or have overcome that sense of helplessness.”

Physical

- retrospective: “That helpless feeling overcomes me when I see my physical health declining.”
- prospective: “That helpless feeling overcomes me when my health suddenly plays tricks on me.”

Intrapersonal

- retrospective: “That helpless feeling overcomes me when I compare my ideals with my actual life.”
- prospective: “That helpless feeling overcomes me when I no longer know what it’s all about.”

Interpersonal

- retrospective: “That helpless feeling overcomes me when I contemplate my trust relationship with others.”
- prospective: “That helpless feeling overcomes me when I try to form relationships.”

Religious

- retrospective: “That helpless feeling overcomes me when I think about my relationship with God.”
- prospective: “That helpless feeling overcomes me when I try to reach God.”

Statistical analyses

To validate the conceptual model of tragic experience (figure 1) empirically we made an oblimin factor analysis. To determine whether tragic experience varies with neurological and neuropsychological characteristics, and with demographic, worldview-related and ecclesiastic characteristics we used Pearson correlations in the case of independent variables at a metric level, and Kruskal-Wallis rank order variance analyses in the case of independent variables at a nominal level ($p < .05$).

5 TRAGIC EXPERIENCE

After removing six of the 24 items on tragic experience on statistical grounds, oblimin factor analysis of parents’ responses to the remaining 18 yielded

three factors instead of the four we had anticipated on the basis of the conceptual model (appendix 1). Together the three factors have an explained variance of 64%. The first factor pertains to physical tragic experience. The second, which loads both the intrapersonal and the interpersonal items, relates to personal tragic experience. The third relates to religious tragic experience. The dichotomy into retrospective and prospective occurs in all three factors (figure 2).

Figure 2. *Tragic experience from an empirical perspective*

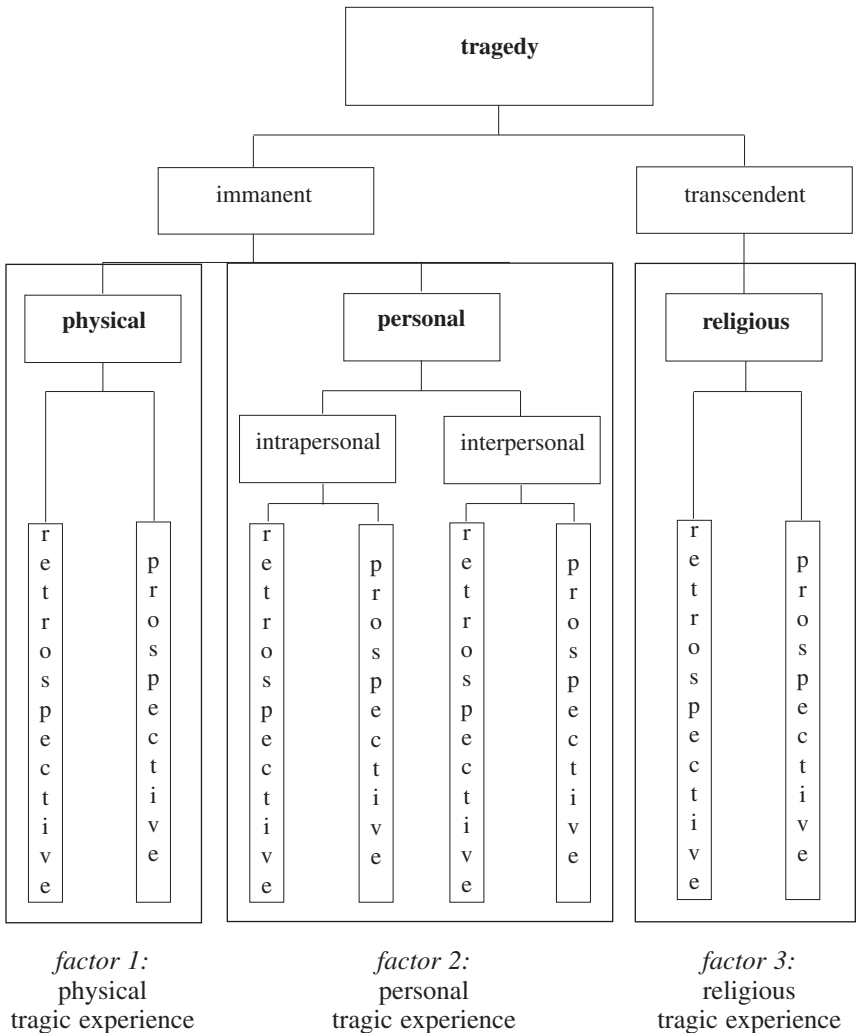


Table 1 shows the mean values and standard deviations of tragic experience among both mothers and fathers.

Table 1. *Tragic experience among parents of children with spina bifida*

	Mothers (N = 44)		Fathers (N = 38)	
	Mean	SD	Mean	SD
Physical tragic experience	2.6	.88	2.4	.86
Personal tragic experience	2.3	.90	2.1	.74
Religious tragic experience	2.1	.91	1.7	.77

Range 1-5 (1 = 'very weak', 5 = 'very strong')

The answer to question 1 ('To what extent do parents of young spina bifida patients have tragic experiences?') is as follows. If we take a score of between 2.0 and 2.9 to mean some measure of tragic experience, it appears that this is the case among both mothers and fathers, except for religious tragic experience among fathers. The mean values moreover display a declining pattern: from physical (2.6, 2.4) through personal (2.3, 2.1) to religious tragic experience (2.1, 1.7). There are no significant differences between the tragic experience of mothers and fathers.

6 TRAGIC EXPERIENCE AND NEUROLOGICAL AND NEUROPSYCHOLOGICAL SYMPTOMS

In this section we distinguish between the following neurological symptoms: type of spina bifida, paresis, presence or absence of hydrocephalus and a shunt. In addition we distinguish between the following neuropsychological symptoms: the child's intelligence, emotional problems and behavioural problems as reported by parents.

Type of spina bifida

Spina bifida is a neural tube defect originating in early pregnancy. The neural tube is the as yet undeveloped tissue that will eventually form the spinal cord. Spina bifida results from incomplete transformation from a neural plate into a neural tube resulting in a malformation of the spine and spinal cord. In this study spina bifida has been classified into three types: myelo(meningo)cele (MC), lipomyeloschizis (LMS), and a-typical forms (ASB). In the first type, myelo(meningo)cele, the malformed spinal cord tissue is exposed at the surface through a midline defect in the back. Mostly, a cele

containing cerebral spinal fluid is visible at the back. Lipomyeloschizis, the second type, is characterized by a subcutaneous fatty mass associated with malformed spinal cord tissue. These lesions are usually skin-covered. A-typical spina bifida cannot be categorised under either of the first forms. Thirty-three children have myelo(meningo)cele (MC), 10 have lipomyeloschizis and three have an a-typical form (ASB).

To determine whether tragic experience varies significantly with the three forms of spina bifida we conducted the Kruskal-Wallis test. It indicated no significant variation in any category, neither among mothers nor among fathers.

Paresis

Paresis refers to the functional lesion level. The position of the lesion in the spinal column influences the patient's mobility. Generally it is accepted that the higher up the lesion, the lower the mobility, implying that lesion level determines the severity of spina bifida.² We classified our spina bifida patients into three groups in terms of severity of paresis. The first group (n = 16) comprises patients whose lesions are in the lower part of the spinal column (sacral level), implying that their spina bifida is considered less serious. The second group (n = 24) have lesions mainly in the middle part of the spinal column (lumbal level), entailing severely impaired mobility. The patients in the third group (n = 6) have a lesion near the top (thoracal level), which means that their spina bifida is considered very serious indeed.

To determine whether tragic experience varies significantly with the three lesion levels we conducted a Kruskal-Wallis test. It revealed two significant variations – physical and personal tragic experience among mothers; there was no significant variation among fathers (tables 2 and 3).

Table 2. *Tragic experience and paresis among mothers*

	sacral (N = 16)	lumbal (N = 22)	thoracal (N = 6)	
	Mean Rank	Mean Rank	Mean Rank	Significance
Physical tragic experience	21.16	19.23	38.08	.00
Personal tragic experience	24.72	18.27	32.08	.04
Religious tragic experience	24.38	19.68	27.83	.28

Table 3. Tragic experience and paresis among fathers

	sacral (N = 13)	lumbal (N = 22)	thoracal (N = 6)	
	Mean Rank	Mean Rank	Mean Rank	Significance
Physical tragic experience	20.88	18.30	22.33	.72
Personal tragic experience	21.50	17.73	23.83	.48
Religious tragic experience	19.15	20.18	16.00	.81

Hydrocephalus and shunt

Hydrocephalus (water on the brain) is a condition where there is too much fluid in the brain. The excess fluid puts pressure on the brain, which can affect brain functioning. By inserting a shunt the fluid is drained mechanically, thus relieving the pressure on the brain. In our research group 70% of the children have hydrocephalus, and all of these have shunts.

To determine whether tragic experience varies significantly with the presence of hydrocephalus and shunts we conducted a Kruskal-Wallis test. It revealed no single significant variation, either among mothers or among fathers.

Intelligence

Intelligence (IQ) was measured by means of the Wechsler Intelligence Scale for Children-III (WISC-III), which measures both verbal and performance (spatial skills) IQ (Kaufman & Lichtenberger, 2000).

Table 4 reflects a mean IQ total score of 82.1, which is considered below average.

Table 4. Mean IQ scores

	Mean	SD	Maximum	Minimum
Verbal IQ score	87.9	17.9	52	122
Performance (nonverbal) IQ score	78.3	20.6	45	126
Total IQ score	82.1	19.3	47	116

To determine whether tragic experience varies significantly with IQ we performed Pearson correlation analyses. These revealed no significant variation.

Patients' emotional and behavioural problems

The spina bifida patients' emotional and behavioural problems were measured by means of the Child Behaviour Checklist/6-18 (CBCL), developed by Thomas M. Achenbach. The questionnaire covers eight key syndromes (118 items altogether), distinguishing between internalising problem behaviour (introversion, physical ailments, cognitive and attention problems, anxiety, depressiveness) and externalising problem behaviour (delinquent and aggressive behaviour). Summing the scores on the 118 items yields a total problem score index, which enables one to determine in which area the child falls: normal (score = 60), borderline (score 60-63) or clinical (score = 63). Scores in the borderline area indicate considerable problems but are just below the clinical level (Verhulst, Van der Ende & Koot, 1996).

Table 5 shows that the total mean score for emotional problems and behavioural problems is 56,6, implying that they fall in the normal area.

Table 5. *Mean scores on behavioural problems of spina bifida patients*

Scale	Mean	SD
Internalisation score	53.6	11.17
Externalisation score	51.1	10.07
Total score behavioural problems	56.6	8.72

To determine whether tragic experience varies significantly with behavioural problems we performed Pearson correlations analyses. These revealed no significant variation.

Question 2 reads: "To what extent do parents' tragic experiences vary with the patients' neurological and neuropsychological symptoms?" We found only two instances of significant variation, both confined to the mothers. Their physical and personal tragic experience appears to vary with paresis.

7 TRAGIC EXPERIENCE AND DEMOGRAPHIC, WORLDVIEW-RELATED AND ECCLESIASTIC CHARACTERISTICS

In this section we examine whether tragic experience varies with parents' demographic, worldview-related and ecclesiastic characteristics. As demographic characteristics we took the ages of both parents and child, and the parents' educational level. The worldview-related attribute is the saliency of worldview to parents, that is the normative importance they attach to

their worldview for their everyday lives. Ecclesiastic characteristics are parents' church membership and church attendance.

Age

The mean age of the children in our research group is 10.3 years, that of mothers is 39.2 years and that of fathers 41.6 years (table 6).

Table 6. *Age of parents and patient*

	N	Mean	SD
Child's age	46	10.3	2.4
Mother's age	44	39.2	4.0
Father's age	36	41.6	4.6

To determine whether tragic experience varies significantly with the ages of child and parents we performed Pearson correlation analyses. They revealed no significant variation. The correlation between child's age and father's personal tragic experience is relatively high (r.26), and that between father's age and religious tragic experience slightly lower (r.19) (table 7).

Table 7. *Pearson correlations between tragic experience and ages of parents and patients*

Mothers (N = 44)	Physical tragic experience	Personal tragic experience	Religious tragic experience
Child's age	.06	-.04	-.09
Mother's age	.09	.01	.06
Fathers (N = 38)	Physical tragic experience	Personal tragic experience	Religious tragic experience
Child's age	.12	.26	-.10
Father's age	.13	.01	.19

Educational level

Among the mothers 73,2% completed a lower level of education and 26,6% have a higher qualification. The respective percentages among fathers are 63,9% en 36,1% (table 8).³

Table 8. *Educational level of the parents*

	Mothers		Fathers	
	N	%	N	%
Lower education	31	73.8	23	63.9
Higher education	11	26.2	13	36.1

Application of the Kruskal-Wallis test shows no variation of tragic experience with educational level among either mothers or fathers.

Worldview saliency

This refers to the importance parents attach to their worldview for their everyday lives (Felling et al. 2000, 66). The mean values are 2.7 for mothers and 2.5 for fathers, indicating that worldview does play some role in their day-to-day living.

Table 9. *Frequencies worldview saliency among mothers and fathers*

	N	Mean	SD
Mothers	44	2.7	.99
Fathers	38	2.5	1.07

To determine whether tragic experience varies significantly with parents' worldview saliency we performed Pearson correlation analyses. Among both mothers and fathers the only significant correlation was between religious tragic experience and worldview saliency ($r=.52$, $r=.61$); the correlations with physical and personal tragic experience were not significant (table 10).

Table 10. *Pearson correlations between tragic experience and worldview saliency*

	Mothers (N = 44)	Fathers (N = 38)
Physical tragic experience	.08	.19
Personal tragic experience	.32	.08
Religious tragic experience	.52*	.52*

Church membership

Fifty percent of the mothers consider themselves to be members of a church, while the remaining 50% are doubtful or negative about their church membership, as opposed to 55.3% of fathers who claim to be church members and 44.7% who are either uncertain or negative.

Table 11. *Church membership among mothers and fathers*

	Mothers	Fathers
Yes	50%	55,3%
No/not sure/doubtful	50%	44,7%

To determine whether tragic experience varies significantly with church membership we applied the Kruskal-Wallis test. Among both mothers and fathers it revealed significant variation with religious tragic experience but not with physical and personal tragic experience (tables 12 and 13).

Table 12. *Tragic experience and church membership among mothers*

	Yes (N = 22)	No/not sure/doubtful (N = 22)	
	Mean Rank	Mean Rank	Significance
Physical tragic experience	20.98	24.02	.44
Personal tragic experience	25.32	19.68	.14
Religious tragic experience	28.27	16.73	.00

Table 13. *Tragic experience and church membership among fathers*

	Yes (N = 21)	No/not sure/doubtful (N = 17)	
	Mean Rank	Mean Rank	Significance
Physical tragic experience	18.93	20.21	.72
Personal tragic experience	19.12	19.97	.81
Religious tragic experience	23.62	14.41	.01

Church attendance

Among mothers 25% attend a church service about once a month; among fathers the percentage is close on 16%. Among both mothers and fathers a good 34% attend church once or several times each year. Of the mothers nearly 41% never go to church; the corresponding percentage for fathers is 50% (table 14).

Table 14. *Church attendance among mothers and fathers*

	Mothers	Fathers
Yes, about once a month	25%	15,8%
Yes, once or several times a year	34,1%	34,2%
No, (almost) never	40,9%	50%

To determine whether tragic experience varies significantly with church attendance we applied the Kruskal-Wallis test. As in the case of church membership, there are significant variations among both mothers' and fathers' tragic experience and church attendance (tables 15 and 16).

Table 15. *Tragic experience and church attendance among mothers*

	Yes, about once or several (N = 11)	Yes, about never times a year (N = 15)	No, (almost) (N = 18)	
	Mean Rank	Mean Rank	Mean Rank	Significance
once a month				
Physical tragic experience	23.55	21.60	22.61	.93
Personal tragic experience	28.77	22.07	19.03	.14
Religious tragic experience	33.64	19.43	18.25	.00

Table 16. *Tragic experience and church attendance among fathers*

once a month	Yes, about once or several (N = 6)	Yes, about never times a year (N = 13)	No, (almost) (N = 19)	
	Mean Rank	Mean Rank	Mean Rank	Significance
Physical tragic experience	24.50	17.00	19.63	.38
Personal tragic experience	24.25	16.88	19.79	.40
Religious tragic experience	28.00	24.04	13.71	.00

Question 3 reads: "To what extent do parents' tragic experience vary with their demographic, worldview-related and ecclesiastic characteristics?" The analyses revealed that among both mother and fathers religious tragic experience varies with worldview saliency, church membership and church attendance.

8 DISCUSSION

In response to question 1, which concerns the extent to which parents of children with spina bifida experience tragedy, we established that three kinds of tragic experience occur, but not to any appreciable degree. In response to question 2, about the extent to which these tragic experiences vary with the child's neurological and neuropsychological symptoms, we found that this applies only to mothers, and then only in the case of physical and personal tragic experience. These two kinds of experience appear to vary with paresis. In response to question 3, regarding the extent to which tragic experience varies with parents' demographic, worldview-related and ecclesiastic characteristics, we found that among both mothers and fathers religious tragic experience varies with worldview saliency, church membership and church attendance (table 17).

Table 17. *Summative table of significant variations*

	Physical tragic experience		Personal tragic experience		Religious tragic experience	
	Mothers	Fathers	Mothers	Fathers	Mothers	Fathers
Paresis	+		+			
Saliency					+	+
Church membership					+	+
Church attendance					+	+

Table 17 presents two pictures. The first is this: of the neurological and neuropsychological symptoms of children with spina bifida paresis alone features significantly, and even then only among mothers. Mothers' physical and personal tragic experience appears to vary with the severity of their children's spina bifida, at least where functional lesion level is concerned. According to the data the extent of both kinds of tragic experience is greatest in the case of high, thoracic lesions, the most serious kind with the most detrimental effect on the child's mobility (table 2). The sense of helplessness that marks tragic experience generally emerges clearly when parents are confronted daily with the grave physical and personal consequences for children with a severe form of spina bifida. The fact that mothers rather than fathers have these physical and personal tragic experiences is probably attributable to the (largely still prevalent) traditional role division, according to which mothers take more responsibility for the care of their children, including those with spina bifida, than fathers. As a result they are confronted more frequently and more intensely with their children's physical and personal suffering.

The second picture that emerges from table 17 is that religious tragic experience varies with worldview saliency, church membership and church attendance. No matter how one assesses religious tragic experience, worldview saliency (i.e. the importance attached to a personal – usually religious – worldview for daily life) appears to predispose people to have religious tragic experiences. This applies equally to those who regard themselves as church members and attend a service at least once a month. It is explained by the fact that the religious traditions, in which churches celebrate their liturgy and devise their proclamation, training and education, abound in images, symbols, stories, poems and rites that epitomise the fragility and finitude of life and express that fragility and finitude in the presence of God. According to Darwin (2004, 105) human beings are the only living species that reflects on their origin and purpose, life and death, and the fragility

and finitude of life – an Existentiale, as Heidegger (1993, 235-267) would put it, that is essential to their humanity. Religion especially, one could add to (or even contradict) Darwin's statement, offers the symbolic and ritual armoury to protect this Existentiale against repression and keep it alive.

NOTES

1. The Nijmegen Interdisciplinary Spina Bifida (NISB) research programme is committed to promoting the care of children with spina bifida and their families. The participating institutions and researchers are:

University Medical Centre St Radboud, Nijmegen:

– Department of Paediatric Neurology (N. Geerdink MD, R. Mullaart MD PhD, J. Rotteveel MD PhD)

– Department of Medical Psychology (A. Vinck MSc, B. Maassen MSc PhD)

– Department of Epidemiology and Biostatistics (N. Roeleveld MSc PhD)

Radboud University Nijmegen:

– Institute of Family and Child Care Studies (I. Vermaes MSc, J. Gerris MSc PhD, J. Janssens MSc PhD)

– Department of Empirical Theology (M. van den Heuvel MA, J. van der Ven MA PhD, H. Schilderman MA PhD)

2. Four levels of mobility (ambulation level), developed by Hoffer (1973), are commonly recognised:

- community ambulator: indoors or outdoors, crutches with or without braces (sacral)
- household ambulator: only indoors, crutches with or without braces (lower lumbar)
- Non-functional ambulator: wheelchair, crutches and braces in therapy (upper lumbar)
- nonambulator: wheelchair bound (thoracic)

In our study the lower and upper lumbar groups were combined into a single lumbar group

3. For the purpose of this study a lower level of education includes lower and intermediate vocational education (LBO and MBO), lower and intermediate technical education (LTS and MTS) and lower general secondary education (MAVO). Higher education includes higher general secondary education (HAVO), higher vocational education (HBO), pre-university education (VWO) and university education (WO).

BIBLIOGRAPHY

- Darwin, Ch. (2004). *The descent of man and selection in relation to sex*. London: Penguin
- De Mul, J. (1994). De domesticatie van het noodlot. *Lot in eigen hand? Reflecties op de betekenis van het (nood)lot in onze cultuur*, P. van Tongeren (ed.). Baarn: Gooi & Sticht.
- Felling, A., Peters, O., Schreuder, O. (2002). Religion in Dutch society 2000. Amsterdam: Steinmetz Archive.
- Guardini, R. (1950). *Vrijheid, genade, lot*. Antwerp: Sheed & Ward.
- Heidegger, M. (1993). *Sein und Zeit*. Tübingen: Max Niemeyer Verlag
- Hoffer, M.M., Feiwell, E., Perry, R., Perry, J., Bonnett, C. (1973). Functional ambulation in patients with myelomeningocele. *The Journal of Bone & Joint Surgery*, 55(1): 137-148.
- Kaufman, A.S., Lichtenberger, E.O. (2000). *Essentials of WISC-III and WPPSI-R assessment*. New York: John Wiley

- Merleau-Ponty, M. (1945). *Phénoménologie de la perception*. Paris: Gallimard.
- Scherer-Rath, M. (2001). *Lebenssackgassen. Herausforderung für die pastorale Beratung und Begleitung von Menschen in Lebenskrisen*. Münster: LIT.
- Van der Ven, J.A. (1991). Religieuze variaties: religie in een gesecculariseerde en multiculturele samenleving. *Tijdschrift voor Theologie* 31(2), 163-182
- Verhulst, F.C., Van der Ende, J. & Koot, H.M. (1996). *Handleiding voor de CBCL/4-18*. Rotterdam: Erasmus Universiteit.
- Vermeer, P.A.D.M. (1999). *Learning theodicy: the problem of evil and the praxis of religious education. An empirical-theological study*. Leiden: Brill.
- Zuidgeest, P. (2001). *The absence of God. Exploring the Christian tradition in a situation of mourning*. Leiden: Brill.
- Internet:
<http://www.amershamhealth.com/medcyclopaedia/medical/Volume%20VI%20I/LIPOMYELOMENINGOCELE.asp>

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APPENDIX

Table: *Factor analysis of tragic experiences (oblitin)*

Item	h ²	Factor 1 (personal)	Factor 2 (religious)	Factor 3 (physical)
When I see what has become of me	.72	.83	-.11	-.11
When I compare my ideals with my actual life	.59	.79	.06	.02
When I try to form relationships	.64	.76	.03	.11
When I want to tell others something about myself	.70	.76	.03	.18
When I contemplate my trust relationship with others	.69	.64	-.18	.17

Table (cont.)

Item	h ²	Factor 1 (personal)	Factor 2 (religious)	Factor 3 (physical)
When I look back on my relations with others	.54	.63	.00	.19
When I think about the state of my marriage/partnership	.34	.60	-.03	-.08
When I think about my life	.65	.58	-.18	.22
When I look back on my attempts to encounter God	.91	.18	-.88	-.16
When I feel abandoned by God	.73	-.07	-.87	.08
When I no longer experience God's love	.65	-.15	-.83	.19
When I think about my relationship with God	.56	.02	-.73	.07
When I try to reach God	.80	.33	-.72	-.16
When I see what God still means to me today	.53	.28	-.58	-.13
When I see my physical health declining	.66	.01	-.16	.76
When my body no longer offers any resistance	.70	.08	-.16	.75
When my health suddenly plays tricks on me	.57	.11	.20	.72
When my energy flags	.55	.26	-.08	.56
Alpha		.92	.92	.86
Total explained variance = 64,1%				

Items eliminated:

8_15 When I no longer know what it's all about.

8_23 When I am indecisive

8_24 About certain occurrences with other people

8_4 When I'm dissatisfied with myself

8_8 When I think how strong and beautiful used to be

8_10 When I think of all the things my body used to be capable of

Factor Correlation Matrix

Factor 1	Factor 2	Factor 3	
Factor 1	1.00000		
Factor 2	-.50234	1.00000	
Factor 3	.43410	-.18591	1.00000