

Coping with Twins Discordant for Intellectual Disabilities: The Mothers' View

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In this exploratory study of 15 families with a twin-pair, of which one has an intellectual disability, the Nijmegen Questionnaire on Childrearing Situations (NQCS) was used to ask mothers about their perceptions and experiences of parenting. An interview with the mothers was done to understand the initial stages of coping with this double problem: educating a twin-pair and a child with an intellectual disability. Four groups of mothers were identified, depending on whether they accepted the intellectual disability of their child and/or whether they perceived their children as a twin-pair or not. Finally, some critical questions for further research and management were formulated.

In the last decade the number of multiple pregnancies has increased significantly (Imaizumi, 1997) largely due to the introduction of assisted reproductive techniques (i.e., in vitro fertilisation and ovulation induction). Since 1997, in Flanders (Belgium), 48 % of the registered twins have been the result of iatrogenic pregnancies. This significant increase is a matter of general concern, especially the higher rates of pre-term (< 37 weeks) delivery and low birth-weight infants (< 2500 g) among twins compared to singletons, and due to this, the inordinate contribution of these infants to overall mortality, morbidity and long-term handicap (Keith, 1994).

Since both congenital malformations and developmental problems are more common in twins, a double problem is faced: in a family already stressed by a multiple birth (Colpin et al., 1998), there is an extra load caused by the presence of a child with an intellectual disability (Bruce et al., 1996; Cant, 1992; Crnic & Booth, 1991; Dalbert & Warndorf, 1996; Dale, 1996; Gresnigt & Gresnigt-Strengers, 1975; Harris, 1987; Joosten, 1990; Trute, 1995; Versteegen, 1978).

Practical, medical, emotional and financial problems cause stress to families raising twins. The parenting of a child with an intellectual disability confronts parents with a discrepancy between expectations and reality. The process of acceptance and coping can take a long time depending on facilitating factors.

Aim of the Study

The parenting of twins and living with a child with an intellectual disability are two topics that are often explored in the literature. Much less is known about the combination of these two aspects. Bryan (1992) calls it not only a 'loss of the perfect child', but also 'the loss of the perfect twin'. The present study focussed on the perception and experience of mothers with a twin-pair of which one has a normal development and the other an intellectual disability, with the aim of better understanding their feelings and questions about parenting within this special situation.

Materials and Methods

Participants

Participating families were selected from the East Flanders Prospective Twin Survey (EFPTS). Since 1964, EFPTS has been collecting information about the mother, the placenta and the children of 98% of the multiple births in the province of East Flanders, Belgium (Loos et al., 1998). At the end of 1998, the register totalled 5371 twin-pairs, 196 sets of triplets and 27 sets of higher order multiple births. Zygosity of the twins was determined based on sex, foetal membranes, umbilical cord blood groups (ABO, Rh, CcDdEe, MNSs, Duffy, Kell), placental alkaline phosphatase and, more recently, DNA fingerprints. Unlike-sex twins and same-sex twins with at least one different genetic marker were classified as dizygotic (DZ); monozygotic twins were classified as monozygotic (MZ). For all same-sex dichorionic twins with the same genetic markers a probability of monozygosity was calculated using a lod-score method (Meulepas et al., 1988; Vlietinck, 1986).

The participants for this study came from a project on cognition in twins (Jacobs et al., 2001). All twins from the EFPTS register born between September 1982 and December 1991 (age range 7–14) from Belgian ancestry were invited to participate. The study sample was representative for gender, birth weight and gestational age. The final

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sample consisted of 663 twin-pairs of which 186 were monozygotic, 100 were dizygotic MZ and 377 DZ. All twins were tested using the Wechsler Intelligence Scale for Children-Revised (WISC-R) (Wechsler, 1986).

From this sample 16 families were selected of which one twin had an IQ > 90 and the other an IQ < 80. These 16 include all of the participating families in the study on cognition in twins with this discordance.

Methods

Families received a letter from the EFPTS inviting the mother to participate in the study; its aim was explained and information given about practical aspects was given. One week later an educational psychologist telephoned verifying the letter's receipt by the family and asking whether they had any questions. If the parents consented to participate, the Nijmegen Questionnaire on Childrearing Situations (NQCS) was sent for the mothers to complete. Later an interview was arranged.

The NQCS (Wels & Robbroeckx, 1986) is based on the Stress-model of Lazarus (Lazarus et al., 1970) and Weiners Attribution-theory. It measures subjective feelings of parenting and parenting-stress (which they described as cognitive emotional taxation) of the education of the twin-pair by the parents themselves. Mothers filled in the NQCS twice, once for each twin.

In a second phase, the mothers were interviewed at home. The answers given in the NQCS were used as interview-guidelines. Questions on the initial stages (the twin-pregnancy, first feelings, delivery, first signs of a difference in development...) were asked because experiences and feelings at the time of the study can be influenced by earlier experiences and thoughts. The interview with the mother was audio-taped. Analysing and scoring the NQCS-data was done in a standardised way as explained in

the manual (Wels & Robbroeckx, 1986). Audio-taped interviews were introduced in a word-document and studied by content analysis. The software-program QSR NUD*IST4 (Geenen, 1999) was used for the qualitative analysis of the content of the interviews.

The analysis of each family was treated as a case study. Based on the individual analyses, three main topics were distinguished.

The first was about the peculiarity of having twins. The second was about acceptance of a child with an intellectual disability. The last was the general perception of parenting by mothers in this 'double' situation.

Results

Fifteen of the 16 families (see Table 1) consented to participate in the study: 3 with MZ and 12 with DZ twins. All MZ twins were males. In the DZ pairs there were 6 male-male pairs, 2 pairs with two females each and 4 mixed pairs. Of the 3 MZ twins, 2 were monozygotic and 1 dizygotic. In 10 of the 15 twins the firstborn has an IQ lower than 80 and the second born an IQ above 90. The age of the 30 children varied between 9 and 18 years, with a mean age of 12.9 years.

Four groups of mothers could be distinguished (see Table 2):

- (1) Those who see their children as a twin-pair AND have accepted the intellectual disability of one child.
- (2) Those who see their children as a twin-pair AND have *not* accepted the intellectual disability of one child.
- (3) Those who do not see their children as a twin-pair AND have accepted the intellectual disability of one child.
- (4) Those who do not see their children as a twin-pair AND have *not* accepted the intellectual disability of one child.

Table 1

Selected Families

Twin-Pair	Age	Sex		IQ		Zygoty	Other disabilities	Group (see table 2)
		Twin 1	Twin 2	Twin 1	Twin 2			
1	12	M	M	77	98	DZ		1
2	13	M	F	97	79	DZ	visual problems (F)	2
3	17	M	M	77	94	MZ		4
4	17	M	M	77	92	MZ		3
5	15	F	F	50	92	DZ		non-response
6	13	M	M	79	94	DZ		3
7	13	M	F	73	110	DZ		3
8	13	M	M	76	94	DZ		3
9	13	M	F	94	68	DZ	ADHD (M) -brain-damage (F)	4
10	12	M	M	79	98	DZ		3
11	12	F	F	76	95	DZ		3
12	10	M	M	50	120	DZ	dyspraxia	4
13	14	M	M	137	67	DZ	autism	4
14	14	M	M	98	79	MZ		3
15	11	F	F	108	71	DZ		3
16	9	M	F	116	67	DZ		4

Table 2

Mothers with a Twin-Pair, of which One Has an Intellectual Disability: Acceptance of the Disability and /or Consideration of Children as a Twin-pair

		Acceptance	
		yes	no
Considering children as a twin-pair	yes	<i>N</i> =1	<i>N</i> =1
	no	<i>N</i> = 8	<i>N</i> = 5

Acceptance is determined according to one of the eight categories in the manual of the NQCS. Mothers with a higher score compared to the norm-population are in the 'non-acceptance' group and mothers with a lower score in the 'acceptance' group.

The four groups are typically characterised as follows:

Group 1

This mother considers her children as a twin-pair and has accepted the intellectual disability of her child. This could be explained by the fact that:

- The child with the intellectual disability does not have behaviour problems.
- There is no large discrepancy between the IQ's of both children.
- The mother can count on the support of her husband and her environment.

She, however, still has questions about the cause of the intellectual disability of her child.

Group 2

This mother considers her children as a twin-pair but has not accepted the intellectual disability. But:

- She does not experience the parenting as a burden.
- There are no remarkable behaviour problems.
- Neither of the children attend a school for special education.

This mother is a single parent. She does not feel she receives much support or help from her family, nor from her environment.

Group 3

These mothers do not consider their children as a twin-pair and have accepted the intellectual disability of their child. A certain realism can be noted: they do not perceive their children as 'the same'.

Factors here are:

- The IQ's of both children do not differ that much from each other.
- The family distress is not to do with the intellectual disability of the child.
- As the children in this group are the oldest, so the problems of acceptance and coping are possibly already past.

The need of emotional support is large. They missed talking with other parents in the same situation.

Group 4

These mothers do not consider their children as a twin-pair and have not accepted the intellectual disability of their child. They live with the discrepancy between reality and the expectations they had about a twin.

The following factors seemed to have an effect:

- The large discrepancy between the children's IQs.
- The child with the intellectual disability goes to a school for special education or lives in an institution.
- The mother is a perfectionist.

Mothers do receive support from their husbands, but some needs remain:

- The need for emotional support: talking with other parents in the same situation.
- Information about the intellectual disability and about the possible cause.
- Concern about the future.

Some said they had not to been able to find professional support.

Firstly, this study shows that almost all the mothers no longer perceive their children as a twin-pair. Thirteen of the 15 mothers consider their twin-pair as two brothers or sisters, or as a brother and a sister. The twin-aspect was not important and did not play a role in daily life.

Secondly, regarding acceptance, differences were not that large. Out of 15 families, 9 mothers have accepted the intellectual disability of their son or daughter.

Finally, mothers perceiving parenting as a burden have not accepted the intellectual disability of their child and no longer consider their children as a twin-pair. They struggle with the discrepancy between reality and what could be. In the normal twin, they see constantly how the other could have been.

Discussion and Conclusion

The increasing number of multiple births and their higher risks of morbidity and long-term handicap compared to singletons, means that health care professionals are confronted with an ever growing group of handicapped twins who need special care and parents who need help in learning to cope.

This exploratory and descriptive study is the first reported on such families. Results based on a study in 15 families may not be generalised. Further research is needed in order to formulate suggestions about management by professional caregivers.

Since mothers indicated that there were extra problems during the early years more research with mothers with younger twins is needed. Fathers' perception of parenting needs to be evaluated and also the response of the unaffected child (who may suffer from all the extra attention given to his or her twin).

Raising twins is especially difficult when one of them has an intellectual disability. We established that the mothers who experience the most problems are those who have expectations of a twin as 'the same' or 'equal' and want to keep it that way. The discrepancy between expectations and reality is the highest for these mothers, and it is

difficult for them to cope with these feelings. The emphasis in advising these families should be on the individuality and personality of each child and on the acceptance that all children are different, even twins.

Acknowledgments

The East Flanders Prospective Twin Survey is partly supported by the Association for Scientific Research in Multiple Births (Belgium). The research on intellectual disabilities in twins, was funded by the Marguerite-Marie Delacroix Foundation.

References

- Bruce, E. J., Schultz, C. L., & Smyrniotis, K. X. (1996). A longitudinal study of the grief of mothers and fathers of children with intellectual disability. *British Journal of Medical Psychology*, *69*(1), 33–45.
- Bryan, E. M. (1992). *Twins, triplets and more. Their nature, development and care*. London: Penguin Books.
- Cant, R. (1992). Friendship, neighbouring and the isolated family: The case of families with disabled children. *International Journal of Sociology of the Family*, *22*(2), 31–50.
- Colpin, H., Nys, K., Vandemeulebroecke, L., & De Munter, A. (1998). *Opvoeden van een meerling* [Parenting multiples]. Leuven, Belgium: Katholieke Universiteit Leuven, Centrum voor Gezinspedagogiek — Kind en Gezin.
- Crnic, K. A., & Booth, C. L. (1991). Mothers' and fathers' perception of daily hassles of parenting across early childhood. *Journal of Marriage and the Family*, *53*(4), 1042–1050.
- Dalbert, C., & Warndorf, P. K. (1996). Ein behindertes Kind — Eine Familienentwicklungsaufgabe: Überprüfung eines dreidimensionalen Gerechtigkeitsmodells familialer Belastungen. [A child with intellectual disabilities — A family-development approach: a 3-dimensional model of justice for family distress]. *Zeitschrift für Entwicklungspsychologie und Pädagogische Psychologie*, *28*(4), 336–356.
- Dale, N. (1996). *Working with families of children with special needs*. London/New York: Routledge.
- Geenen, G. (1999). *Ongepubliceerde nota's bij 'Practicum Hermeneutische Observatie en Interpretatie': Een introductie tot QSR NUD*IST 4*. [An introduction to QSR NUD*IST 4.]. Leuven, Belgium: K.U.Leuven.
- Gresnigt, H. A. A., & Gresnigt-Strengers, A. M. C. (1975). *Ouders en gezinnen met een diepzwakzinnig kind*. [Parents and families with a child with severe intellectual disabilities]. Amsterdam: Swets & Zeitlinger.
- Harris, S. L. (1987). The family crisis: Diagnosis of a severely disabled child. *Marriage and Family Review*, *11*(1–2), 107–118.
- Imaizumi, Y. (1997). Trends of twinning rates in ten countries, 1972–1996. *Acta Geneticae Gemellologiae*, *46*(4), 209–218.
- Jacobs, N., Van Gestel, S., Derom, C., Thiery, E., Derom, R., Vernon, P., & Vlietinck, R. (2001). Heritability estimates of intelligence in twins: Effect of chorion type. *Behavior Genetics*, *31*, 209–217.
- Joosten, J. (1990). Bronnen van participatieve belasting van moeders in gezinnen met een gehandicapt kind: de aandoening of het gezin? [Sources of participative distress in mothers in families with a child with disabilities: the disease or the family?]. *Mens en Maatschappij*, *65*(3), 245–270.
- Keith, L. (1994). Mortality and morbidity among twins: Recent observations from the United States. *Acta Geneticae Medicae et Gemellologiae*, *43*(1–2), 25–31.
- Lazarus, R., Averill, J. R., & Opton, E. M. (1970). Towards a cognitive theory of emotion. In M. B. Arnold et al. (Eds.), *Feelings and emotions*. New York: Academic Press.
- Loos, R., Derom, C., Vlietinck, R., & Derom, R. (1998). The East Flanders Prospective Twin Survey (Belgium): A population-based register. *Twin Research*, *1*, 167–175.
- Meulepas, E., Vlietinck, R., & Van den Bergh, H. (1988). The probability of dizygosity of phenotypically concordant twins. *American Journal of Human Genetics*, *43*, 817–826.
- Trute, B. (1995). Gender differences in the psychological adjustment of parents of young, developmentally disabled children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *36*(7), 1225–1242.
- Verstegen, M. C. G. (1978). *Het geestelijk gehandicapte kind en zijn ouders: Ouders als hulpvragers en hulpverleners in de zwakzinnigenzorg*. [The child with an intellectual disability and his parents: Parents as care-askers and care-givers in the management for people with disabilities]. Lochem, Belgium: De Tijdstroom.
- Vlietinck, R. (1986). *Determination of the zygosity of twins*. Unpublished doctoral thesis, Katholieke Universiteit Leuven, Leuven.
- Wechsler, D. (1986). *Wechsler Intelligence Scale for Children — Revised (Dutch version)*. Lisse, the Netherlands: Swets & Zeitlinger.
- Wels, P. M. A., & Robbroeckx, L. M. H. (1986). Gezinsbelasting. Begrip, model, operationalisatie en onderzoek. [Family distress. Meaning, model, operationalisation and research.] In J. R. M. Gerris (Ed.), *Pedagogisch onderzoek in ontwikkeling*. Nijmegen, the Netherlands: ITS.