

Attitudes of mothers and staff towards treatment and possible outcomes of very low-birth-weight (VLBW) infants in Bloemfontein

David J Griessel, MB ChB, MMed (Paed)

Department of Paediatrics and Child Health, Faculty of Health Sciences, University of the Free State, Bloemfontein

Gina Joubert, BA, MSc

Department of Biostatistics, Faculty of Health Sciences, University of the Free State, Bloemfontein

Mohale Setlaba, MB ChB III student

Orapeleng Seboco, MB ChB III student

Lloyd Chokoe, MB ChB III student

School of Medicine, Faculty of Health Sciences, University of the Free State, Bloemfontein

Corresponding author: D Griessel (GriesselDJ@ufs.ac.za)

Objectives. In neonatal intensive care units (NICUs), difficult decisions about care and withdrawal of treatment sometimes have to be taken by parents and healthcare workers, especially when the infant will probably have a poor developmental outcome. Only one previous study conducted in South Africa investigated whether preferences in this regard differ between these groups. We aimed to acquire more information on the issue.

Design. A comparative cohort study comprising separate groups.

Setting. Neonatal units of Universitas Academic and Pelonomi Regional hospitals.

Subjects. Mothers of very low-birth-weight (VLBW) babies and children with multiple disabilities; paediatricians (including registrars) and nurses working in these units.

Outcome measures. The preferences for developmental outcomes were compared between four groups: nurses, paediatricians, mothers of VLBW infants, and mothers of babies with multiple disabilities. Different scenarios were illustrated, and questionnaires were used to obtain the opinions on active treatment for babies with a poor developmental outcome.

Results. When asked whether doctors should attempt to save premature babies, even with a more than 50% chance of being handicapped, 100% of mothers agreed, as opposed to 23% of paediatricians. Similar results were obtained when respondents were asked whether they would prefer to have a severely handicapped child rather than no children at all. Seventy per cent of mothers of VLBW babies indicated that parents are the most important stakeholders in NICU decision making.

Conclusions. Doctors may underestimate mothers' capacity to cope with handicapped children. The opinion and perspectives of mothers are therefore important factors in NICU decision making.

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Advances in medical technology during the past 25 years have made it possible to save very low-birth-weight (VLBW; <1 500 g) and extremely low-birth-weight (<1 000 g) infants who previously would not have survived. Vexing ethical questions remain. Which newborns are so small or immature that neonatal care should not be implemented? Once initiated, should such care be withdrawn if severe complications occur? Who should be involved in these decisions? Although some doctors feel that they are in the best position to determine which infants should and should not receive potentially life-saving interventions, it is increasingly recognised that parents, who must live with the consequences of the decision, should be actively involved in decisions regarding the treatment of these children.¹

The significant long-term morbidity and socio-economic costs of attending to these babies are becoming apparent. As a result, calls have been made for a reappraisal of neonatal intensive care of the smallest babies on ethical, moral, social and economic grounds.² With recent improvements in the survival of infants of borderline viability, the issue of whether such infants should be treated actively continues to be debated.³ However, shared decision making between healthcare professionals on the one hand, and parents on the other, raises several issues. It has been shown that parents are less willing than medical staff to withdraw life support from infants who would have a moderate level of disability.⁴

In a recent survey among physicians in European countries, it was found that the parents' attitude towards treatment might have an influence on the decisions concerning the care of their infants, although extensive individual and cultural differences were evident.⁵ In a single South African study reported in the literature, considerable differences in attitudes between medical staff and mothers were found, with mothers being much more conservative in their approach to the withdrawal of treatment.⁶

Since much room for potential conflict exists, it is important to understand the perspectives of the different parties involved in the care of VLBW babies.⁷ When mothers have raised and cared for a child with disabilities, their experience may have an influence on their attitude towards the treatment of VLBW babies.⁴

Although the issue has been debated by healthcare experts of diverse persuasions, little has been done to obtain information from the parents of VLBW infants on how they perceive their lives to have been affected, or what their opinions were with regard to active treatment of such babies. No investigation into this matter has been performed in the neonatal units of the Universitas Academic and Pelonomi Regional hospitals in Bloemfontein. Consequently, the authors believed that it would be meaningful to investigate parents' attitudes towards active treatment of VLBW infants and compare them to the opinions of the staff responsible for caring for these babies.

The aim of the study was to compare the attitudes of medical staff with those of mothers of VLBW babies, as well as mothers of children with multiple disabilities, towards active treatment and possible outcomes of VLBW babies. In particular, we investigated their views on treatment even when there is a high risk of disability, who they believed should be involved in the decision making, and their personal feelings with regard to the outcome of a theoretical 'own baby'.

Methods

A comparative cohort study comprising separate groups was conducted. These groups included: (i) the mothers of VLBW babies; (ii) the mothers of children with multiple disabilities; and (iii) paediatricians (including registrars) and nurses working in the neonatal units of the Universitas Academic and Pelonomi Regional hospitals.

The first study population included mothers of consecutive VLBW babies born in either of these two hospitals from 1 June 2004 to 30 September 2004. The hospitals were visited by the researchers almost daily to identify babies born during the preceding 24 hours. The second study population consisted of mothers bringing their children with disabilities to the neurodevelopmental clinic during the same 4-month period. The third study population comprised medical and nursing staff working in the neonatal units of the two hospitals. No exclusion criteria were applied, and all mothers and staff who gave consent were interviewed. We attempted to get at least 70% participation from the staff and 90% from the mothers; these objectives were achieved.

A questionnaire, available in either English or Sesotho, was used to capture information. Participants' age, race, socio-demographic information, level of education, marital status, employment status, religious participation and family composition, and whether there were children with disabilities in the family, were determined by means of the questionnaire. Five standardised hypothetical health scenarios⁸ were portrayed, to which participants had to indicate their response. They were prompted by the statement 'I would prefer a child with these problems rather than not having a child at all.' A four-point Likert scale ranging from 'strongly disagree' (1) to 'strongly agree' (4) was used. These scenarios are listed in Table 1. The children in these scenarios were given fictitious unisex names.⁸ Sesotho names

were used on the Sesotho questionnaire. The researchers interviewed the mothers and completed the questionnaires on their behalf, while the questionnaire was self-administered by members of the medical and nursing staff.

Five participants from each of the three population groups were interviewed in a pilot study to test the questionnaire.

Data were analysed by the Department of Biostatistics, University of the Free State (UFS). Results were summarised by frequencies and percentages (categorical variables) and means, standard deviations or percentiles (numerical variables). Groups were compared using chi-square tests or Fisher's exact tests with relative risks.

Ethical approval to conduct the study was obtained from the Ethics Committee, Faculty of Health Sciences, UFS. Permission to carry out the interviews with the mothers and staff was granted by the Head: Clinical Services of the respective hospitals.

Results

The demographic details of participants are shown in Table 2. One hundred and thirty participants were involved in the study, of whom 17 (13.1%) were paediatricians, 39 (30.0%) nurses, 55 (42.3%) mothers of VLBW babies, and 19 (14.6%) mothers of children with multiple disabilities. The median age of paediatricians was 34 years, of nurses 36 years, of mothers of VLBW babies 26 years, and of mothers of children with disabilities 32 years. Three (7.7%) of the nursing staff were students in their final year of study and were therefore not employed on a full-time basis. The unemployment rate among mothers of VLBW babies was 63.7%, and among mothers of children with disabilities 63.2%. Twenty (36.4%) mothers of VLBW babies and 5 (29.4%) mothers of children with disabilities had completed secondary education up to grade 12. The majority of participants indicated their religion as Christian, and most of them participated in religious activities on at least a monthly basis. Seven (12.7%) of the mothers of VLBW babies had family members with disabilities.

Participants' responses to the hypothetical health scenarios of the five children described in Table 1 are summarised in Table 3. The results reflect the frequency and percentage of participants in each group who chose either option 1 or option 2 on the Likert scale (that is, either strongly agreed or agreed, respectively) that they would rather have the child described than not having a child at all.

The only scenario for which statistically significant differences were noted between the groups of participants was with regard to the child named Pat/Relebohile. Paediatricians differed significantly ($p < 0.01$ for multiple comparisons) from mothers of VLBW babies and mothers of children with multiple disabilities.

On the issue whether doctors should make an effort to save extremely premature babies regardless of birth weight, even with a 50% chance of being handicapped if the child survived, a statistically significant difference between the groups' responses was observed. Among mothers of children with disabilities and VLBW babies, 100% agreed or strongly agreed with the statement, while 66.7% of nurses and 23.5% of paediatricians supported the statement. Paediatricians differed significantly ($p < 0.01$ for multiple comparisons) from all other groups, and nurses differed significantly from all other groups.

Participants were asked whether they would still want the doctors to try and save the baby if they were informed that the baby was suffering from a complication that would lead to a serious handicap, for example blindness or paralysis. The mothers of VLBW babies and children with multiple disabilities agreed that they would want the baby to be saved (96.4% and 94.7%, respectively), as opposed to 69.2% of nurses and 29.4% of paediatricians. Paediatricians differed

Table 1. Descriptions of the adapted hypothetical health scenarios presented to participants⁸

Jamie/Mpumelelo

- Able to see, hear and speak normally for age
- Able to walk, bend, lift, jump and run normally for age
- Generally happy and free from worry
- Learns and remembers schoolwork more slowly than classmates as judged by parents or teachers
- Eat, bathes, dresses, and uses the toilet normally for age

Chris/Sipho

- Able to see, hear and speak normally for age
- Requires the help of another person to walk or get around and requires mechanical equipment as well
- Occasionally fretful, angry, irritable, anxious, depressed, or suffering 'night terrors'
- Learns and remembers schoolwork normally for age
- Can eat, bathe dress and use the toilet normally
- Free of pain

Alex/Sello

- Able to see, hear and speak normally for age
- Able to walk, bend, lift, jump and run normally for age
- Occasionally fretful, angry, irritable, anxious, depressed, or experiencing 'night terrors'
- Learns and remembers schoolwork normally for age
- Eats, bathes, dresses and uses the toilet normally for age

Sandy/Thandi

- Sees, hears or speaks with limitations even with equipment
- Requires mechanical equipment (such as canes, crutches, braces or wheelchair) to walk or get around independently
- Occasionally fretful, angry, irritable, anxious, depressed, or suffering 'night terrors'
- Learns and remembers schoolwork very slowly and usually requires special educational assistance
- Requires mechanical equipment to eat, bathe, dress or use the toilet independently
- Occasional pain; discomfort relieved by non-prescription drugs or self-control without disruption of normal activities

Pat/Relebohile

- Blind, deaf or mute
- Requires mechanical equipment (such as canes, crutches, braces or wheelchair) to walk or get around independently
- Generally happy and free from worry
- Requires the help of another person to eat, bathe, dress or use the toilet
- Occasional pain; discomfort relieved by non-prescription drugs or self-control without disruption of normal activities

significantly ($p < 0.01$ for multiple comparisons) from all other groups, and nurses differed significantly from mothers with VLBW babies.

In all groups 89% or more of the participants indicated that doctors and parents were the most important stakeholders in making decisions, except for the mothers of VLBW babies, of whom only 69.1% indicated that parents are the most important.

Discussion

Doctors and nurses exhibited an attitude towards treatment and possible outcome with emphasis directed towards avoidance of significant handicap. Mothers of VLBW babies were more positive about the possibility of severe handicap and preferred more aggressive treatment in babies with a possible poor outcome. These important differences in outlook were also found in Asian,⁹ Canadian^{4,10,11} and South African⁶ studies.

In our study, the fathers' opinions could not be determined because more than 50% of the mothers who participated in the study were unmarried, and also because many of the fathers were unavailable. Mothers in both groups felt that it was the doctor's duty to save lives irrespective of outcome, and many included their religious belief in God's will as a reason why they would treat all babies. From the demographic information, it was found that, in comparison with paediatricians, a higher percentage of mothers of children

with disabilities were churchgoers, which may partly explain the differences in their views on treatment.

Wainer and Khuzwayo⁶ conducted a study in 1992 at Baragwanath Hospital and compared 55 health professionals and 70 mothers of recent neonatal intensive care survivors. Their cohort of mothers was also predominantly unmarried and poorly educated, similar to the mothers in our study. Only 2.9% of mothers would consider withdrawal of life support from a child with probable moderate handicap, as opposed to 57% of the medical staff. These doctors also gave the perceived burden that a handicapped child places on the family as a reason for their beliefs.⁶

We consulted the example of a Canadian study investigating the preference for selected health states from the perspectives of healthcare professionals, parents of VLBW babies and adolescents who were VLBW or normal birth weight infants.⁴ We used their hypothetical health states in our study, but not their method, the standard gamble approach. Such an approach involves parents having a chance of treatment effecting a cure of the child's health state versus a percentage risk of the child dying. We decided against this method because its reliability has not been tested in South Africa, and instead used the less complex Likert scale. In the Canadian study, 64% of professionals and 45% of parents rated existence with severe disabilities to be a health state worse than death.⁴

Table 2. Socio-demographic data of participants

	Paediatricians (n=17)		Nurses (n=39)		Mothers of VLBW babies (n=55)		Mothers of children with disabilities (n=19)	
	n	%	n	%	n	%	n	%
Married	9	52.9	20	51.3	19	34.5	9	47.4
Employed full-time	17	100.0	36	92.3	18	32.7	7	36.8
Level of education								
Grade 12	17	100.0	39	100.0	20	36.4	5	29.4
Diploma/degree	17	100.0	35	89.7	5	9.1	3	20.0
Christian religion	15	88.2	39	100.0	52	94.6	18	94.7
Participation in religious activities at least monthly	13	76.5	37	94.9	23	78.2	18	94.7
Race								
White	15	88.2	4	10.3	1	1.8	5	26.5
Black	1	5.9	33	84.6	50	90.9	12	63.2
Coloured	0	0	2	5.1	4	7.3	2	10.5
Other	1	5.9	0	0	0	0	0	0
Person with disability in immediate family	0	0	2	5.1	7	12.7	19	100.0

Table 3. Frequency and percentage of participants who agreed that they would rather have the child described than not having a child at all

Child	Paediatricians (n=17)		Nurses (n=39)		Mothers of VLBW babies (n=55)		Mothers of children with disabilities (n=19)	
	n	%	n	%	n	%	n	%
Jamie/Mpumelelo	15	93.8	31	79.5	47	85.5	18	94.7
Chris/Sipho	12	75.0	25	64.1	39	70.9	18	94.7
Alex/Sello	15	93.7	33	84.6	43	78.2	18	94.7
Sandy/Thandi	4	25.0	20	51.3	29	52.7	13	68.4
Pat/Relebohile	3	18.7	19	48.7	31	57.4	15	78.9

Although not directly comparable, our results showed that 81% of paediatricians and 50% of nurses felt that it was better not to have a child like that (same scenario) compared with 42% of mothers of VLBW babies. Remarkably, only 21% of mothers of children with disabilities showed this preference. Our study therefore added a unique perspective, namely the positive attitude of mothers living with a severely handicapped child. Lam *et al.*⁹ performed a study in Hong Kong with a similar design, and also found that parents of preterm infants were most likely to save the infant at all costs and also showed more tolerance for severe disability health states.⁹

It must be asked why these differences exist, and debated whether they should translate into actions, advice and advocacy, with obvious ethical implications in a time of family-centred neonatal care. The mothers of children with disabilities were exposed to the reality of having the child for a few years, and the fact they had time to adjust to the problems of daily living with their child, may have rendered them more accepting. Although the positive attitude of mothers may be tinged by denial, it also seems that the healthcare professionals underestimate the capacity of parents to cope with handicapped infants.

One criticism of our study might be the fact the mothers of children with disabilities constituted a convenience sample who could attend the neurodevelopmental clinic. They were, however, from a very resource-poor background and probably represented a cross-section of this group in the community.

In the ongoing debate about the active treatment of neonates with a probable poor outcome, it is essential that parents' feelings and perspectives should be respected.^{12,13} Both doctors and nurses should be educated about the results of long-term follow-up of the babies under their care. They should also acknowledge the wishes and rights of parents in any decisions taken to limit care.

Ethical decision making is a process wherein all the voices should be heard, and the findings of our study should be an integral part of the debate.

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Conflict of interest statement. The authors have no conflict of interest to declare.

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