



Parental perception of neonatal intensive care in public sector hospitals in South Africa

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Background. Little is known about parental experience and decision making with regard to premature infants requiring intensive care in developing countries. We undertook this study to characterise parents' experience of physician counselling and their role in making life-support decisions for very low-birth-weight (VLBW) (birth weight < 1 501 g) infants born in South Africa's public-sector neonatal intensive care units (NICUs).

Methods. Parents of surviving VLBW infants treated in three Johannesburg-area public hospitals and attending follow-up clinics in August 2001 were interviewed regarding their experience of perinatal counselling on outcomes (pain, survival, disability), perception of actual and optimal decision making, and satisfaction with NICU communication.

Results. Parents of 51 infants were interviewed. Seventy-five per cent of parents reported antenatal counselling by physicians on at least one perinatal topic (severe disability,

pain, death, finances or religious/moral considerations). The majority of parents (> 60%) who received counselling thought that these topics had been discussed adequately. Most parents reported that doctors had the primary decision-making role, either without consulting them (41%) or after consulting them (37%). Joint decision making was rare (14%). Parents wanted more input in life-support decisions than they reported being given.

Conclusion. Counselling is not consistently provided in public-sector hospitals in Johannesburg. Parents of premature infants want a larger share in NICU decision making than they currently experience. Most parents were satisfied with communication later during their infant's hospitalisation. South Africa presents a unique opportunity to study the use of advanced medical technologies in a nation with marked disparities in access to care.

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The limit of viability in developed countries has decreased among extremely low-birth-weight (ELBW) infants, i.e. those weighing less than 1 001 g.^{1,2} Neonatal intensive care has also improved outcomes for some prematurely born infants in South Africa.³ However, neonatal intensive care unit (NICU) bed shortages sometimes preclude intensive care;⁴ in some under-served areas two-thirds of infants born in the public sector lack access to neonatal units.⁵ Accordingly, infants weighing < 1 000 g are not routinely ventilated in public-sector hospitals in South Africa, and physicians may be 'less aggressive' than parents would like.⁶ More widespread care of premature infants in public hospitals would strain already limited national economic resources, increasing costs of treating the neurological and physical disabilities among survivors of extreme prematurity.^{2,7,8}

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Previous studies in South Africa have evaluated parent and provider attitudes towards hypothetical NICU scenarios.⁶ We investigated parents' experiences of physician counselling and parents' role in actual life-support decisions for very low-birth-weight (VLBW) (birth weight < 1 501 g) infants born in South Africa's public hospitals.

Methods

Participants

We interviewed parents of surviving VLBW (< 1 501 g) infants attending NICU follow-up clinics, regardless of gestational age, condition at birth, or inborn/outborn status. Parents were eligible if their newborn infant had been admitted to public-sector NICUs at Johannesburg General Hospital, Coronation Hospital, or Chris Hani Baragwanath Hospital, all of which serve predominantly low-income patients in Johannesburg.

Procedures

In July - August 2001, parents were enrolled during their infant's follow-up clinic appointment. Study personnel (JCP, TMR) then conducted 20-minute interviews in private rooms with the assistance of nurse translators. Given the linguistic diversity and low literacy rates in South Africa, we used nurses



who translated questions into the appropriate language and back-translated parent responses.

The interview tool, originally developed for parent interviews in California and Australia,⁹ was modified for cultural and medical relevance in South Africa. Questions were Likert-scale graded responses or yes/no questions regarding parent demographic information, the infant's health status, parent experiences and satisfaction with perinatal physician counselling on potential outcomes (survival, disability, pain), parent perceptions of actual and optimal decision making, and overall satisfaction with the NICU experience. Interviews allowed opportunities for open-ended responses.

Statistical analysis

Analysis was performed using the Stata statistical package (Stata Corporation, College Station, Texas, USA). A chi-square two-sample test of proportions was used for comparison of proportions. Wilcoxon's signed-rank test was used to compare paired data with ordinal outcomes. We considered p -values < 0.05 significant.

Institutional review boards at the University of California, San Francisco and the University of the Witwatersrand approved the study. Interviewed parents were compensated for travel expenses, and nurse translators for their time.

Results

Sample demographics

We interviewed 51 parents of 51 surviving infants (data not reported for one twin who died). No parent refused an interview. Demographic data for parents and their infants are presented in Table I. The majority of interviewed parents were mothers, with a mean age of 28 years. The majority of parents were Christian (74%), Zulu-speaking (48%), and had completed more than 8 years of schooling (74%). The average infant gestational age was 30 weeks. The average birth weight was 1 163 g; 14 infants weighed less than 1 001 g at birth. Females comprised 57% of infants. The median infant age at interview was 4 months.

Antenatal counselling

A minority of parents reported physician counselling on each topic (severe disability, pain, death, finances, or religious/moral considerations) during perinatal care (Fig. 1). However, 75% of parents reported discussion of at least one topic. Over 60% of parents reported that physicians had not counselled them on estimated mortality. Eighty per cent of parents did not recall their physicians discussing the option of withholding resuscitation at delivery. Many parents said they were not counselled regarding the possibility of severe disability (49%),

Table I. Demographic characteristics of interviewed parents and infants (N = 51)

| Characteristics | Value |
|------------------------------------------|-----------------|
| Parents | |
| Mean age (years, \pm SD) | 28 \pm 6 |
| Sex (%) | |
| Female | 98 |
| Male | 2 |
| Religion (%) | |
| Christian | 74 |
| None | 18 |
| Hindu | 2 |
| Muslim | 2 |
| Traditional | 2 |
| Race or ethnic group (%) | |
| Zulu | 48 |
| Tsetswana | 16 |
| Xhosa | 10 |
| Shangaan | 8 |
| Sotho | 6 |
| Ndebele | 4 |
| Venda | 2 |
| Banda | 2 |
| Swazi | 2 |
| Caucasian | 2 |
| Years of schooling | |
| 0 - 4 years | 2 |
| 5 - 8 years | 24 |
| 9 - 12 years | 41 |
| 13 - 16 years | 27 |
| > 16 years | 6 |
| Infants (N = 51) | |
| Median (range) age at interview (months) | 4 (1 - 17) |
| Mean (\pm SD) gestational age (weeks) | 30 \pm 2 |
| Mean (\pm SD) birth weight (grams) | 1 163 \pm 187 |
| Infants born < 1 001 g (N) | 14 |
| Sex (%) | |
| Female | 57 |
| Male | 43 |

SD = Standard deviation.

pain (55%), death of their child (61%), or financial (74%) or religious/moral (78%) considerations. There were no differences in age, schooling, ethnicity or religion between those who received and those who did not receive perinatal counselling. Compared with parents of infants weighing $\geq 1 000$ g at birth, parents of infants weighing $< 1 001$ g (ELBW) were more likely to report being adequately counselled regarding disability (64% v. 35%, $p < 0.03$), finances (50% v. 11%, $p < 0.01$) and moral/religious issues (50% v. 11%, $p < 0.01$). While not significant, more parents of ELBW infants recalled physicians discussing estimated survival than did parents of infants weighing $> 1 000$ g at birth (57% v. 32%, $p = 0.053$). Perceived adequacy of counselling did not differ between parents of infants born at ≤ 28 weeks versus ≥ 29 weeks.

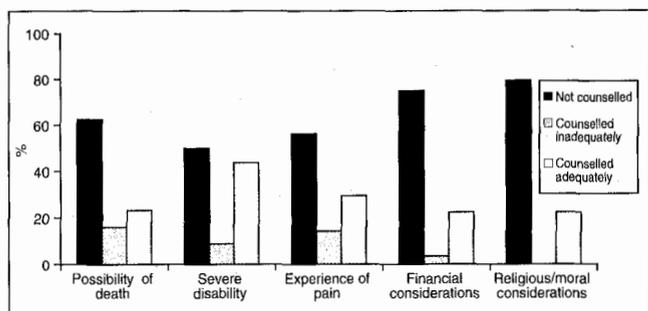


Fig 1. Perinatal counselling (N = 51).

The majority of counselled parents perceived that severe disability, pain, death, finances or religious/moral considerations had been adequately discussed (Fig. 1). Parents with 12 or more years of schooling were more likely to report inadequate discussion of disability (56% v. 18%, $p < 0.01$, chi-square analysis). Perceived adequacy of counselling was not statistically correlated with parental age, ethnicity or religion.

Decision making

The majority of parents indicated that doctors had played a primary role in NICU decisions about resuscitation and life support (Table II). While a majority (88%) agreed with physician recommendations, most parents reported that doctors had made decisions either without consulting them (41%) or after consulting them (37%). Joint decision making was rare (14%), and < 10% of parents themselves made life-support decisions for their infant.

Asked the optimal process for making decisions for NICU infants, 49% of parents preferred joint decision making with physicians and 37% felt that physicians should make the final decision after consulting parents. Less than 10% of parents preferred doctors to make life-support decisions without consultation, and < 10% preferred making decisions without physician involvement. Overall, parents preferred greater input in decision making than they perceived they had been given ($p < 0.01$, Wilcoxon's signed-rank test). Zulu-speaking parents were less likely than non-Zulu-speaking parents to report that doctors should make the final decision (25% v. 63%, $p < 0.01$, chi-square analysis). No relationships between parental age, religion or education and optimal counselling were statistically significant.

Table II. Perceived and optimal life support decision making (N = 51)

| Ultimate decision-maker | Perceived (%) | Optimal (%) |
|----------------------------------|---------------|-------------|
| Doctor alone | 41 | 8 |
| Doctor after consulting parents | 37 | 37 |
| Doctors and parents together | 14 | 49 |
| Parents after consulting doctors | 4 | 6 |
| Parents alone | 4 | 0 |

Parent experience of NICU care

Although a minority of parents recalled antenatal counselling by physicians as adequate, the majority (75%) felt that they understood their infant's condition in the NICU. Parents more commonly reported nurses as being more helpful than physicians in talking about the infant's treatment and status (47% v. 37%). Slightly more than half (57%) of interviewed parents were satisfied with overall communications during NICU care. Nevertheless, two-thirds of parents worried that their baby might die in the NICU, and 27% feared their baby could die after hospital discharge.

Discussion

This is the first study of parental experience of physician counselling and decision making for VLBW infants receiving intensive care in public-sector hospitals in South Africa. In a similar population in South Africa, Wainer and Khuzwayo⁶ demonstrated that parents would prefer more aggressive neonatal intensive care than providers, even when health resources are limited. They concluded that parents played a relatively passive parental role in life-support decisions.⁶ Our results demonstrate the difference between parents' actual experiences and their perceptions of optimal counselling and decision making.

Perinatal counselling

Counselled parents felt that physicians adequately discussed topics relevant to NICU decision making before delivery. Parents of ELBW infants weighing < 1 000 g were more likely to report adequate physician counselling, indicating that physicians may reserve more thorough counselling for patients with worse prognoses. Paradoxically, most parents reported understanding their infant's condition well, whether counselled or not. This disparity may stem from parents' limited understanding of complex medical issues or from explanations given by nurses. Several barriers probably diminish parent involvement in life-support decisions and limit their overall satisfaction with communication in South Africa's public-sector hospitals. Physicians' and nurses' workloads constrain time for extensive discussion, mothers often receive little prenatal care and are discharged 6 hours after uncomplicated deliveries, and poor parents often do not have telephones and cannot visit the nursery frequently.

We did not find demographic differences between parents who did and did not receive counselling. We might expect counselling to differ in private versus public-sector hospitals where resource shortages restrict NICU admissions, but this study was not designed to elucidate these differences.

In multicultural South Africa, particularly in the public sector, language differences complicate physician consultation with parents of VLBW infants. Many physicians cannot





communicate directly with patients and must rely on nurse interpreters. The time necessitated by translation constrains physician counselling and may limit parental involvement in informed decision making. Ethnic differences between patients and physicians may provide yet another obstacle to clear consultation, as attitudes towards health care depend heavily on cultural or religious beliefs.¹⁰

Decision making

The disparity we document between actual and optimal decision making may result from interaction between parent and physician attitudes and behaviours. Wainer and Khuzwayo⁶ showed that South African mothers trust health care providers, despite preferring more aggressive medical treatments than public-sector hospital staff. Our study shows that parents desire a larger share in NICU decision making for their premature infant than they are currently given. Parents do not want physicians to make decisions without their input; neither do they desire sole decision making responsibility. Parent preferences regarding decision making appear in part to be culturally determined, as demonstrated by preferences of Zulu-speaking versus non-Zulu-speaking parents.

Parent satisfaction

Just over half the parents were satisfied with NICU communication, although a significant proportion did not receive comprehensive antenatal counselling by physicians. We have shown that nurses are more often perceived as helpful than physicians, perhaps because nurses share more cultural and linguistic commonalities with patients.¹¹ Nurses spend more time at the bedside and often have to explain medical conditions when physicians are not available. Nurses play an integral role in communicating with and supporting parents. Further training to promote counselling by nurses would probably improve parents' understanding and satisfaction with NICU care.

Conclusions

Limited technological resources and medical and social realities restrict options available for premature infants in South

Africa,^{5,12} aggravating the difficulties of improving NICU care for infants born in the public sector. Increased perinatal counselling would lead to higher rates of parental satisfaction with neonatal care in intensive care units. Improved counselling should allow parents to take a more active decision-making role. Restricted staffing limits the time available for extensive parent counselling by physicians, leaving parents to depend on nurses to help explain their infant's status. More opportunities for counselling could be facilitated by increased access to prenatal care or longer hospitalisation after delivery. Improved counselling, perhaps with more widespread use of trained translators or information pamphlets, should allow parents to take a more active decision-making role. Neither governmental restrictions nor technological limitations should obviate the need to establish consistent parent counselling as a standard of care.

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References

1. Allen MC, Donohue PK, Dusman AE. The limit of viability — neonatal outcome of infants born at 22 to 25 weeks' gestation. *N Engl J Med* 1993; **329**: 1597-1601.
2. Lorenz JM, Wooliever DE, Jetton JR, Paneth N. A quantitative review of mortality and developmental disability in extremely premature newborns. *Arch Pediatr Adolesc Med* 1998; **152**: 425-435.
3. Cooper PA, Saloojee H, Bolton KD, Mokhachane M. Survival of low-birth-weight infants at Baragwanath Hospital — 1950 - 1996. *S Afr Med J* 1999; **89**: 1179-1181.
4. Cooper PA. Very-low-birth-weight infants in South Africa. *S Afr Med J* 1999; **89**: 1160-1161.
5. Rothberg AD, Cooper PA. Rationing versus equity — the South African dilemma. *S Afr Med J* 1999; **89**: 1151-1153.
6. Wainer S, Khuzwayo H. Attitudes of mothers, doctors, and nurses toward neonatal intensive care in a developing society. *Pediatrics* 1993; **91**: 1171-1175.
7. Wood NS, Marlow N, Costeloe K, Gibson AT, Wilkinson AR. Neurologic and developmental disability after extremely preterm birth. EPICure Study Group. *N Engl J Med* 2000; **343**: 378-384.
8. Doyle LW. Outcome at 5 years of age of children 23 to 27 weeks' gestation: refining the prognosis. *Pediatrics* 2001; **108**: 134-141.
9. Millar SD, Epstein L, Schab DW, Partridge JC, Martinez AM. Counseling and decision-making for very low birthweight (VLBW) infants: maternal perspectives. *Pediatr Res* 1999; **45**: A.
10. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Ann Intern Med* 1978; **88**: 251-258.
11. Hansen JD. The role of the doctor in the changing health service. *S Afr Med J* 1978; **54**: 161-165.
12. Cooper PA, Sandler DL. Outcome of very low birth weight infants at 12 to 18 months of age in Soweto, South Africa. *Pediatrics* 1997; **99**: 537-544.

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