

# End-of-life decision making regarding infants of artificial reproductive techniques and spontaneous conception

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**Abstract.** *Objective:* Our goal was to determine if differences exist in the decisions made regarding dying infants based on method of conception. No studies have examined end-of-life decisions for infants regarding method of conception.

*Study design:* We reviewed the charts of infants who were born and died in our institution between January 1, 2001 through December 31, 2005. Method of conception, maternal age, marital status, level of education, religion, insurance, gestational age, cause of death and withdrawal of life-sustaining care were recorded. Statistical analysis was performed using Pearson Chi-squared tests of independence.

*Results:* Fifty-six mother/infant pairs were available for information. Artificial reproduction techniques (ART) were more likely to be utilized by women who were over 35 years old and married ( $p < 0.05$ ). Withdrawal of care was not statistically significant regarding method of conception or gestational age ( $p > 0.05$ ). Although not statistically significant, in this study it appears that single mothers may be less likely to withdraw support.

*Conclusions:* Neither method of conception nor gestation age is a determinant factor in withdrawal of life-sustaining care. Marital status may be an important factor and further investigation is necessary to determine the reason.

**Keywords:** Withdrawal of support, neonate, assisted reproduction, prematurity

## 1. Introduction

As the field of reproductive medicine expands, we learn more about the technological limits and about the emotional and psychological complexity of the patients undergoing these techniques. Many of the families that undertake the process of artificial reproductive techniques (ART) endure a lengthy course that can be filled with disappointments. Most of these families are exposed to emotionally intense consultations with obstetricians, perinatologists and neonatologists. Dur-

ing these consultations, an abundance of information is delivered to the expectant parents.

Parents of infants conceived by ART are more likely to have multiple gestation pregnancies and preterm deliveries [1]. Approximately 30–50% of surviving children who weighed less than 750 g at birth or whose gestational age was less than 25 weeks have moderate to severe disabilities [2]. Even though fewer infants born less than 1000 g are now dying and the greatest improvement has been made in the subgroup of infants born between 450 and 700 g, this is still the group with the greatest likelihood of mortality [3].

We hypothesized that parents of infants conceived by ART might be more prone to withdraw support from critically ill neonates because they were more likely to have exposure to the statistics regarding morbidity and mortality in the premature neonate. If there are differences in the decisions made by parents of spontaneously conceived infants when compared to decisions made

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by infants conceived by ART, we believe such information would be useful in structuring the discussions we have with families with critically ill neonates.

## 2. Methods

The medical records of all infants (and their mothers) who were born alive and subsequently died in The Mount Sinai Hospital (New York, New York) neonatal intensive care unit (NICU) between January 1, 2001 and December 31, 2005 were reviewed. The Mount Sinai Medical Center Neonatal Intensive Care Unit is a regional perinatal center with over 6,000 deliveries per year and 750 admissions to the NICU per year for both medical and surgical care. On average there are 25 deaths per year. Our study only includes data from inborn patients. Transferred patients were not included due to unavailable maternal data.

The data collected included method of conception, maternal age, marital status, level of education, religion, type of insurance, gestational age, cause of death and withdrawal of life-sustaining support. This study was approved by the institutional review board of The Mount Sinai Medical Center.

Statistical analysis was performed by using Pearson Chi-squared tests of independence. Statistical significance was accepted at the  $p < 0.05$  value.

## 3. Results

A total of 63 infants were born in our hospital and subsequently died within the 5 year study period. This total includes all gestational ages greater than or equal to 23 weeks. All of these infants died in our NICU during their first admission. None of the infants were discharged and readmitted. Fifty-six infant/maternal medical records were available for review. Of the remaining 7 infant/maternal medical records, either one or both charts were not available for our use. We had a total of 5 sets of twins and no triplets who died during that period. All but 2 infants in the ART category died  $< 30$  days, most dying within the first few days of life. In the spontaneously conceived category 62% died in the first week, 25% died between 1 week and 1 month of life and the remaining 13% died after 1 month of life. The causes of death were extreme prematurity, NEC, cardiac lesions, pulmonary hypoplasia, hydrops and sepsis. Artificial reproductive techniques were more likely to be utilized by women who were

over 35 years old and married (Fig. 1a and b,  $p < 0.05$ ). All of our ART mothers were privately insured.

Education, religion and gestational age were not statistically significant between our ART mothers and those who conceived spontaneously. In our study the relationship between type of death and religion, education and maternal age were also not statistically significant. When examining gestational age, we chose to divide the infants into periviable (23 0/7 weeks to 24 6/7 weeks) and viable ( $\geq 25$  0/7 weeks) categories because, in our institution, we allow the parents the option of comfort care for infants born less than 25 completed weeks. These periviable infants were included in the withdrawal of support category. We defined withdrawal of support as either withholding or active withdrawal. Three infants received comfort care and therefore resuscitation was withheld.

The remaining 53 infants were withdrawn from ventilatory support. There was no statistically significant difference in the withdrawal of support between those families who conceived using ART and those that conceived spontaneously (Fig. 2,  $p > 0.05$ ). We also found that the gestational age of the infant was not a determinant of withdrawal of support (Fig. 3,  $p > 0.05$ ). Although not statistically significant, it appears that single mothers may be less likely to withdraw support (Fig. 4,  $p = 0.073$ ). This information is also displayed in Tables 1 and 2.

## 4. Discussion

For all parents, end-of-life decisions regarding their children are difficult. While physicians who deal with sick newborns are aware of the complexity of these decisions, there is little in the literature that focuses on specific subsets of families and their uniqueness. Our working hypothesis was that parents of infants who were conceived by ART would be more likely to withdraw life-sustaining support because of their exposure to information concerning potentially poor outcomes for the most immature of these infants. This did not appear to be the case although we realize this study was both retrospective and encompassed a limited number of patients and families.

What we do know is that in our institution mothers who become pregnant using artificial reproductive techniques are more likely to be married and over 35 years old. Many of these women have undergone multiple attempts with ART. The emotional involvement in each of these attempts at pregnancy is likely to be

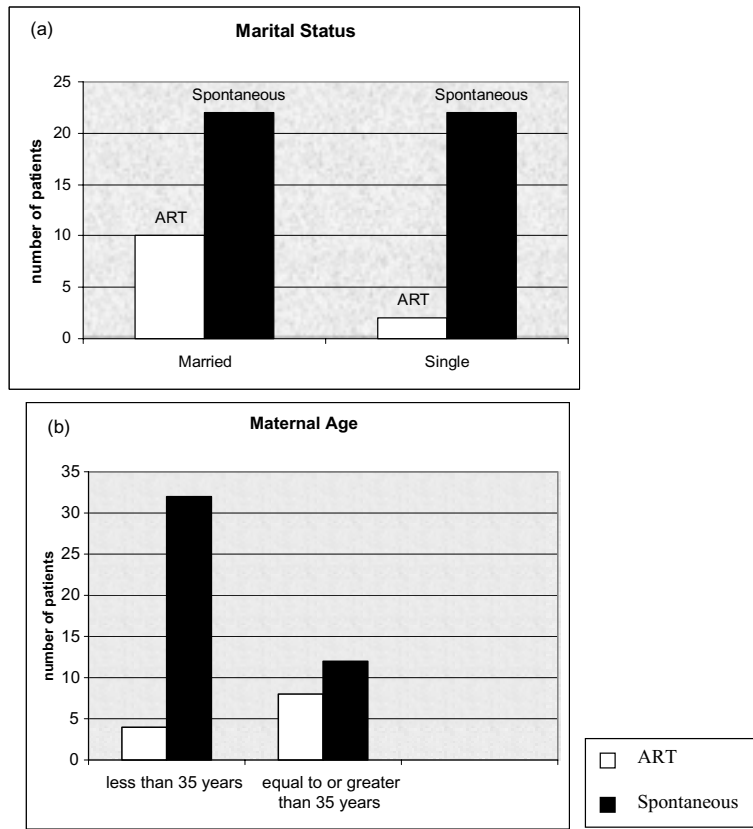


Fig. 1. (a) Marital status of our patients’ mothers who conceived by ART (artificial reproductive techniques) and spontaneous conception. (b) Maternal age of our patients’ mothers who conceived by ART and spontaneous conception.

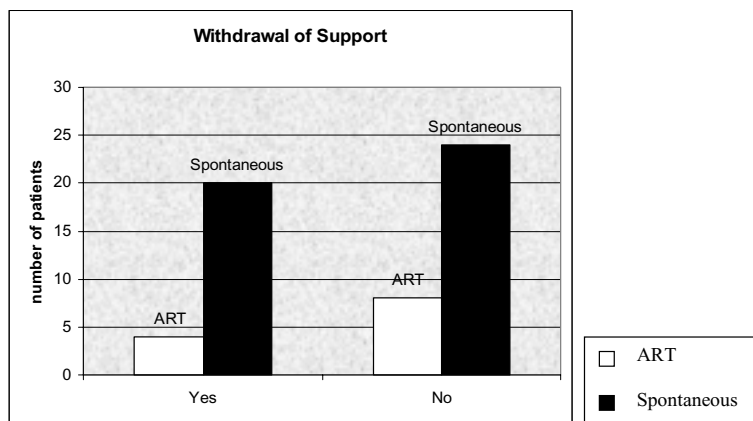


Fig. 2. Withdrawal of support of our patients categorized by method of conception.

very stressful on the hopeful parents. As noted by Barbara Katz Rothman [5], “IVF [*in vitro* fertilization] has made the ability to accept infertility a sign of a weakness: infertility is no longer an ascribed characteristic but now more of a chosen status if only one chosen by default whenever a woman decides to give up.” Some

authors [1] feel that too little information is available about the outcome of the infants conceived by IVF, and that there is potential abuse of women’s bodies in the effort to procreate. Even with all the statistical information provided to ART parents regarding morbidity and mortality of the premature infant, the desire or ex-

Table 1  
Deaths associated with withdrawal of support

	Total number of infants withdrawn from support (n = 24)	
Method of Conception	ART = 4	Spontaneous = 20
Maternal Age	< 35 yrs = 17	≥ 35 yrs = 7
Gestational Age	23/24 wks = 10	≥ 25 wks = 14
Marital Status	Married = 17	Single = 7

Table 2  
Deaths associated with full support

	Total number of infants that died with full support (n = 32)	
Method of Conception	ART = 8	Spontaneous = 24
Maternal Age	< 35 yrs = 19	≥ 35 yrs = 13
Gestational Age	23/24 wks = 13	≥ 25 wks = 19
Marital Status	Married = 15	Single = 17

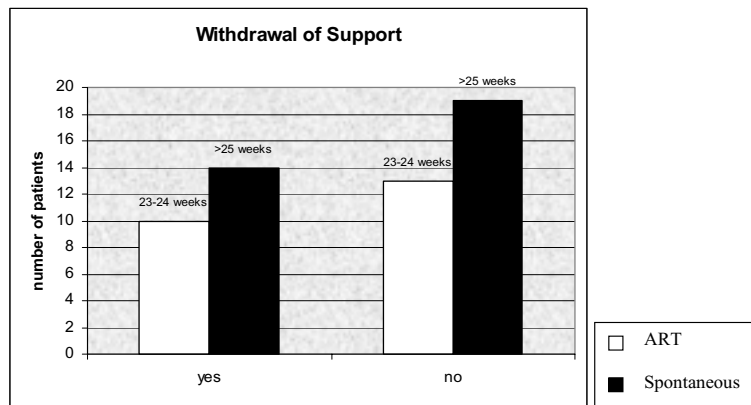


Fig. 3. Withdrawal of support of our patients categorized by gestational age (23–24 weeks gestation vs > 25 weeks gestation).

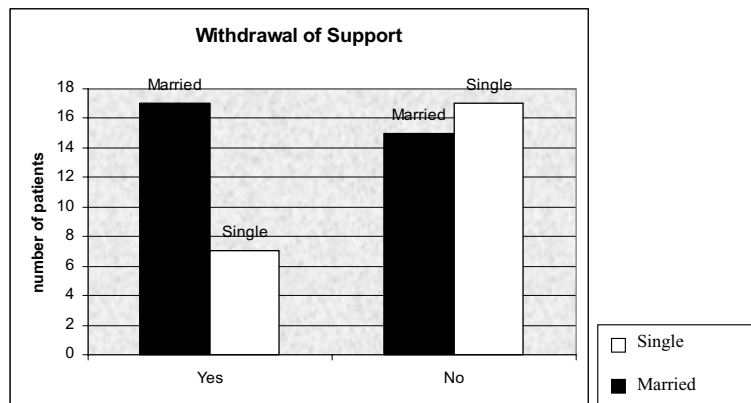


Fig. 4. Withdrawal of support of our patients categorized by mother’s marital status.

pectation to reproduce may outweigh the possibility of a disappointing outcome. The data from the present study seem to support such a view.

Gestational age in our study was not statistically significant between our ART and spontaneously conceived infants. Also, gestational age was not a determinant

of withdrawal of support when using the categories of perivable and viable gestational age. As the field of neonatology grows, more infants are born at the edge of viability. Improvement in care has been the most prominent in the perivable group over time but, this is still the group with the highest mortality [3]. Survival

rates are now reported to be approximately 30% and 50% for 23 weeks gestation and 24 weeks gestation respectively [2]. Most NICU nonsurvivors still expire early, but they are not dying quite as early as they used to [3]. In our study, most of our patients expired within the first week of life. Most of our expectant parents were counseled prior to delivery regarding the potential survival rates and neurodevelopmental outcomes for their infants. Similarly, after delivery families have frequent discussions regarding these issues.

Although it did not achieve statistical significance, there was the suggestion in the data that single mothers were less likely to withdraw life-sustaining care from their infants. One theory to explain this finding could be that single mothers do not want to be the sole decision makers. Paris et al. [4] discuss the unique pattern of end of life decision makers who are single and comment on the special burden such a decision would be for a single person.

Most parents are unfamiliar with the complexities of the care required by an extremely premature infant. Parents should be encouraged to participate actively in discussions regarding delivery and management. A course of action should be chosen that is medically appropriate and consistent with the parents personal values and goals and physicians should avoid characterizing managements of uncertain benefit as “doing everything” or “doing nothing” [2]. Some authors recommend a “trial of therapy” and the option of withdrawing later [6]. This allows parents the option of not making an immediate decision about resuscitation. Singh et al. [6] also recommend offering the parents the option of withholding CPR instead of withdrawal, when death is inevitable.

Our policy at Mount Sinai Medical Center regarding critically terminal infants is as follows. The attending, fellow and resident physicians along with the nurse caring for the infant meet with the family in a quiet setting to discuss the infant’s critical condition. At the end of the discussion, once all the family’s questions have been answered, if appropriate, withdrawal of support is suggested or not intensifying medical support. We also offer comfort care management as an alternative to resuscitation for extremely preterm infants (24 6/7 weeks and less).

## 5. Conclusions

It would appear that parents of infants conceived by ART are not more likely to withdraw life-sustaining support for their infant than parents of infants conceived spontaneously. They seem to feel equally strong about keeping their baby alive, despite the statistical information afforded them, possibly because of the emotional, psychological and financial investments made. Also, the significant stressors experienced by these families during the attempts at conception may have unique effects on their decision making that will require more in-depth examination.

We believe there is a need to acquire more sophisticated information about our expectant parents in order to develop a care plan for their child. This may include removing some of the burden of decision-making by offering a “trial of therapy” as well as the option of not initiating CPR even if withdrawal of support is not an option. Larger, prospective studies of the knowledge base and decision-making patterns of families who deliver premature and fragile infants conceived by ART are needed if we are to meet the emotional needs of this group.

## References

- [1] C. Bellieni and G. Buonocore, Assisted procreation: too little consideration for the babies? *Ethics Med* **22** (2006), 93–98.
- [2] H. MacDonald, American Academy of Pediatrics. Committee on Fetus and Newborn. Perinatal care at the threshold of viability, *Pediatrics* **110** (2002), 1024–1027.
- [3] W. Meadow, G. Lee, K. Lin and J. Lantos, Changes in mortality for extremely low birth weight infants in the 1990s: implications for treatment decisions and resource use, *Pediatrics* **113** (2004), 1223–1229.
- [4] J.J. Paris, N. Graham, M.D. Schreiber and M. Goodwin, Approaches to end-of-life decision-making in the NICU: insights from Dostoevsky’s *The Grand Inquisitor*, *J Perinatol* **26** (2006), 389–391.
- [5] B.K. Rothman, Not all that glitters is gold, *Hastings Cent Rep* **22**(Suppl) (1992), S11–S15.
- [6] J. Singh, J. Lantos and W. Meadow, End-of-life after birth: death and dying in a neonatal intensive care unit, *Pediatrics* **114** (2004), 1620–1626.