

# The Experience of Families With Children With Trisomy 13 and 18 in Social Networks

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## KEY WORDS

trisomy 13, trisomy 18, life-sustaining interventions, quality of life, parental opinions, ethics, end of life decision-making

## ABBREVIATION

T13-18—trisomy 13 and trisomy 18

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**WHAT'S KNOWN ON THIS SUBJECT:** Trisomy 13 and 18 are conditions with 1-year survival rates of less than 10% and have traditionally been treated with palliative care. There are increasing reports of ethical dilemmas caused by parental requests for clinical interventions.



**WHAT THIS STUDY ADDS:** Parents who belong to social networks report an enriching family experience and describe surviving children as happy. Many of these parents describe challenging encounters with health care providers.

## abstract

**BACKGROUND:** Children with trisomy 13 and trisomy 18 (T13-18) have low survival rates and survivors have significant disabilities. For these reasons, interventions are generally not recommended by providers. After a diagnosis, parents may turn to support groups for additional information.

**METHODS:** We surveyed parents of children with T13-18 who belong to support groups to describe their experiences and perspectives.

**RESULTS:** A total of 503 invitations to participate were sent and 332 questionnaires were completed (87% response rate based on site visits, 67% on invitations sent) by parents about 272 children. Parents reported being told that their child was incompatible with life (87%), would live a life of suffering (57%), would be a vegetable (50%), or would ruin their family (23%). They were also told by some providers that their child might have a short meaningful life (60%), however. Thirty percent of parents requested “full” intervention as a plan of treatment. Seventy-nine of these children with full T13-18 are still living, with a median age of 4 years. Half reported that taking care of a disabled child is/was harder than they expected. Despite their severe disabilities, 97% of parents described their child as a happy child. Parents reported these children enriched their family and their couple irrespective of the length of their lives.

**CONCLUSIONS:** Parents who engage with parental support groups may discover an alternative positive description about children with T13-18. Disagreements about interventions may be the result of different interpretations between families and providers about the experiences of disabled children and their quality of life. *Pediatrics* 2012;130:293–298

Trisomy 13 and trisomy 18 (T13-18) are frequently referred to as being “lethal” disorders because of their poor outcomes.<sup>1</sup> The risk of fetal loss during a pregnancy with T13-18 is high.<sup>2</sup> Children born with T13-18 have survival rates beyond 1 year of 6% to 12% and have profound neurodevelopmental disabilities when they survive.<sup>3–7</sup> Some children do not have “full” T13-18 but instead have 1 of many variants of these chromosomal conditions, with outcomes that can be much less severe.<sup>8,9</sup>

The American Academy of Pediatrics Neonatal Resuscitation Program textbook recommends against resuscitation for these conditions.<sup>10</sup> The 2010 American Heart Association guidelines make similar recommendations, on the basis of “unacceptably high morbidity.”<sup>11</sup> A significant number of pregnancy terminations occur after a prenatal diagnosis of T13-18.<sup>7,12,13</sup> Nonetheless, some women continue their pregnancy and may request medical interventions for their child. Parental narratives describe a lack of support and understanding after making choices that are not seen as being acceptable to physicians.<sup>14–17</sup> A small study describes dissatisfaction with health care experiences after a prenatal diagnosis of T18.<sup>18</sup>

Internet social networks are an alternative source of information and support for families after a new diagnosis. In 1997, the first trisomy Internet-based support group was created. By September 2010, at least 18 English-language Internet-based parental support groups dedicated to T13-18 existed (see the Appendix). These groups provide resource information as well as pictures and details about children with T13-18. Many parent groups send a message about T13-18 that seems to be dissonant with the “conventional” clinical view. For example, Web site visitors are often directed to a YouTube video called “99 balloons,” describing the short life of a child with T18 ([www.youtube.com/watch?v=th6Njr-qkQ0](http://www.youtube.com/watch?v=th6Njr-qkQ0)). To date, the

empirical data on the parental perspectives of having a child with T13-18 are limited.

The overall objective of this study was to describe the experiences of parents who are members of social networks and who have (had) children with T13-18. A better understanding of the parental perspective may facilitate communication and decision-making between providers and parents.

## METHODS

A computer-assisted self-completion questionnaire was designed using expert opinion, including focus groups and 2 pretests involving a total of 10 parents. One of the collaborators in this study is a parent (B.F.).

The 18 English-language Web sites and Facebook groups dedicated to T13-18 (see the Appendix) were contacted and 570 e-mail addresses of individuals who had made their e-mail addresses accessible were obtained. Our inclusion criteria were as follows: parents of children who live(d) with full T13-18, mosaicism, and other structural variations involving chromosomes 13 and 18 (called variants in this article). Our exclusion criteria were the following: respondents other than the parent, diagnoses other than T13-18, families who experienced in utero deaths, and incomplete questionnaires.

The 503 potential participants received an e-mail to participate in the study with the Internet link to the study site. They were then sent 3 reminders, with 3 weeks between each reminder. The last reminder was sent in January 2011. The first page of the questionnaire described the nature of the study and asked for their consent to participate by checking a box. Participants could access the survey only if they had checked that box. A 1-use link to the survey was generated for each participant and only responses obtained with this link were accepted to ensure that each individual parent could participate only once. All respondents

were asked 10 open-ended and 12 demographic questions. Questionnaires were considered complete if 6 specific questions had been answered: respondent identification (mother or father); diagnosis of “full” T13 or 18 or other variants, birth date, whether the diagnosis was made prenatally or postnatally, level of medical intervention provided; whether the child died before initial discharge home, and whether the child was living at the time of the survey.

The answers to these questions determined which additional questions were presented: from a minimum of 31 to a maximum of 106 questions.

For questions related to parental perspectives, we analyzed responses from all respondents. For questions related to clinical outcomes, we analyzed responses describing children with full T13-18 and who were still alive. When 2 parents answered questions for the same child, we used only maternal answers. We used descriptive statistics for quantitative data. Open-ended questions were analyzed by the development of themes, the applications of the themes to the responses by 2 authors (A.J. and B.F.), and the resolution of discrepancies by consensus. NVivo 9 (QSR International, Melbourne, Australia) was used to assist with the qualitative analysis.<sup>19,20</sup> This study obtained ethics approval from Sainte-Justine Hospital.

## RESULTS

Between October 2010 and January 2011, 503 e-mails with an invitation to answer the survey were sent. The survey site had 386 visitors with 380 visitors satisfying inclusion criteria. A total of 354 surveys were returned and 332 were completed (87% response rate based on site visits, 67% response rate based on invitations sent).

### Parents and Children

The 332 respondents consisted of 74 fathers and 258 mothers. They

answered questions for 272 children: both parents answered the questionnaire for 60 children; there were only maternal answers for 194 children and only paternal answers for 18 children (Table 1). Most parents (76%) were from the United States, 8% were from Canada, 6% were from the United Kingdom, and 9% were from 12 other countries. When their child with T13-18 was born, the median age of parents was 33 years; 35% were older than 35 years. Seventy percent already had children and 23% had 3 children or more. Almost all parents (99%) completed high school, and most (68%) completed at least 1 university degree, with 25% also completing postgraduate studies. Parents generally described themselves as religious (89%), with 37% not attending religious services. Demographic factors were similar between mothers and fathers and between parents of children with T13 and T18.

A total of 216 children had full T13-18 (Table 2); 44% of these had T13 and 82% were born after 2000. Forty percent lived more than a year and 37% are still alive. Survival to 1 year for children with full T13-18 was 40%, whereas survival to age 5 was 21% (Table 2). Of these 79 living children, 96% with T13 and 91% with T18 are older than 1 year.

### Interventions in Children With Full T13-18

Of these 216 children, 25% received “full intervention as for any child,” and half received comfort care (Table 3). There was no association between the parents’ education or religiosity and the plan of care. Of the 104 newborns who received comfort care, one-third died before hospital

discharge, half died before 3 months of age, and a third lived beyond 1 year (Table 3). Parents of children who died described the overall experience of their child’s life as being positive (88%); 68% had no regrets and 31% regretted that they did not consider more interventions.

Of the 53 newborns who received full interventions, one-third died before discharge, 36% died by the age of 3 months, and half lived beyond 1 year. There were similar proportions of T13 and T18 among the 1-year survivors. Parents of children who died despite interventions described the overall experience of their child’s life as being positive (89%), with 89% reflecting that they made the right decisions, with no regrets. A cardiac malformation was present in 146 children, of which 25 had heart surgery. All children went home after the surgery. Of these, 21 live(d) more than 1 year after surgery and 10 live(d) 5 years after surgery.

### Clinical Outcomes in Children Who Are Currently Living

Seventy-nine children with full T13-18 are living, with a median age of 4 years and 98% live at home. Only 1 child with T18 used a tracheostomy with ventilation, 11% always used supplemental oxygen, 54% sometimes used supplemental oxygen, and 59% had a gastrostomy but some used it only intermittently. The children had significant developmental delays but gained milestones over time (Table 4). Almost all parents (95%) reported they communicated with their children and understood their needs; 99% of parents described their child as a happy child.

## Parental Experiences

### Family Impact

Of the 187 parents whose children died, 89% reported that the overall experience of their child’s life was positive. Of the 159 parents whose child lived longer than 3 months, half stated that their child experienced more pain than other children and half recognized that caring for a special needs child was more difficult than they thought it would be. Yet, 98% reported that this child enriched their life. Of the families in this cohort who had other children ( $n=160$ ), 82% felt that this child had a positive effect on siblings. Of all the parents, 3% report that their marriage dissolved since the diagnosis of T13-18, and 68% stated this child had a positive effect on their relationship.

When all parents were asked if they would continue the pregnancy if they discovered they were expecting another child with T13-18, 8% responded negatively, 9% were unsure, and 83% responded positively or stated that they would not have pursued prenatal testing in the first place.

### Financial Impact

Of the 160 parents who cared for a child who lived more than 3 months, 91% of fathers and 27% of mothers worked full time during their child’s life. Seventy parents (44%) whose child lived longer than 1 year stated they found the financial sacrifices related to their child to be very challenging.

### Interactions With Health Care Providers

Most parents (63%) report they met a special health care provider who helped them but 37% of parents who chose clinical intervention for their child felt judged. Parents reported being told by some providers after their child’s diagnosis that their child was incompatible with life (87%), would live a life of suffering (57%), would be a vegetable (50%), would live a meaningless life (50%), would ruin their marriage (23%) or

**TABLE 1** Description of Parents of Children With T13-18

Characteristic	All Parents ( $n = 332$ ), $n$ (%)	Parents With Full T13-18 ( $n = 261$ ), $n$ (%)
Mother	258 (78)	202 (77)
Father	74 (22)	59 (23)
Parents whose children are still alive	245 (44)	93 (36)
Prenatal diagnosis	128 (39)	114 (44)

would ruin their family (23%). However parents reported that some providers told them that their child may enrich their family (16%), might have a short meaningful life (60%), or might survive for many years (43%). The proportion of parents who reported these comments made about full T13-18 versus variant T13-18 were similar.

In our analysis of the open-ended responses, parents reported appreciating the following from health care providers: referring to the child by name (even if unborn), offering to take pictures (in and ex utero), referring to other families or web sites, and describing not only those

organs that had malformations but also those that did not have malformations. The most common negative comment made by parents was a sense that health care providers did not see their baby as having value, as being unique, as being a baby: "He is not a trisomy 13, his name is Sam"; "For them she was only a genetic label"; "Sarah is human, she is not a diagnosis"; "They never asked what her name was, she was a lethal Tee-18". Parents reported they particularly disliked health care providers calling their fetus or child an "it," a "that," a "vegetable," or a "T13 or T18." They also strongly disliked the following terms:

"incompatible with life," "waste of money/time/energy," "lethal," "there is nothing we can do for him/her," "you can have another one," "this child will hurt you/your family/your children."

## DISCUSSION

We describe the perspectives of 332 members of parent support groups who have children that live(d) with T13 or T18; this is the largest cohort of parents described to date. The children described by these parents had similar birth weights and neurodevelopmental outcomes to those described in population-based studies<sup>6,7</sup>; however, 40% of children with full T13-18 in this study survived longer than 1 year, a rate that is much higher than described in the population studies.<sup>6,7</sup> This cohort of patients is not a representative sample from which one could derive valid population survival figures, as this was not a population sample with a defined time frame and geographical area. Also, we hypothesize that parents whose children survive longer are more likely to join support groups, contributing to inflated survival rates in our results. Most parents in these support groups were American mothers who were "older" than average during their pregnancy.<sup>21,22</sup> They had more children compared with average<sup>23</sup> and were more educated than individuals in the same age group in the United States.<sup>24</sup>

Although most parents described their children as having significant neurodevelopmental disabilities, almost all parents reported a positive view of family life and the quality of life of their child with T13-18. These parents overwhelmingly described surviving children as happy and stated that they were able to communicate with them to understand their needs. Parents seemed to accept their children's limitations and to celebrate their small achievements. When children died, parents viewed their short lives as being valuable. Yet at

**TABLE 2** Description of Children With T13-18

Characteristic	All Children (n = 272), n (%)	Full T13-18 (n = 216), n (%)	Full T13 (n = 94), n (%)	Full T18 (n = 122), n (%)
Prenatal diagnosis	107 (39)	97 (45)	49 (52)	48 (39)
Weighed <5 lb at birth	136 (50)	120 (56)	31 (33)	89 (73)
Still alive	120 (44)	79 (37)	25 (27)	54 (44)
Went home after birth	199 (73)	150 (69)	55 (59)	95 (78)
Lived <6 mo	126 (46)	118 (55)	64 (68)	54 (44)
Lived longer than 1 y	134 (49)	86 (40)	27 (29)	59 (48)
Lived longer than 5 y	73 (27)	45 (21)	17 (18)	28 (23)
Lived longer than 10 y	41 (15)	26 (12)	8 (9)	18 (15)

**TABLE 3** Survival Related to Level of Intervention for Children With Full T13-18 (n = 216)

Level of Intervention	Died Before Discharge, n (%)	Died <1 wk, n (%)	Died <3 mo, n (%)	Lived >1 y, n (%)	Lived >5 y, n (%)
Full intervention (n = 53)	17 (32)	9 (17)	19 (36)	28 (53)	13 (25)
T13 (n = 19)	7 (37)	3 (16)	8 (42)	10 (53)	5 (26)
T18 (n = 34)	10 (29)	6 (17)	11 (32)	18 (53)	8 (24)
In between full intervention and comfort care (n = 59)	12 (20)	12 (20)	24 (41)	27 (46)	15 (25)
Comfort care (n = 104)	37 (36)	36 (35)	54 (52)	31 (30)	17 (16)

**TABLE 4** Neurodevelopmental Milestones of Children With Full T13-18 Who Are Still Alive and at Least 1-Year-Old (n = 64)

Milestones	1-3 y, % (n = 21)	3-10 y, % (n = 20)	More than 10 y, % (n = 23)
Smile	100	100	100
Laugh	95	95	96
Point at objects	5	37	65
Says "mama" or "papa"	24	45	35
Plays with toys	86	95	100
Rolls over	90	100	100
Sits up	24	60	91
Stand with assistance	24	85	91
Stand without assistance	0	20	17
Walk with a walker	5	50	74
Walk unassisted	0	10	0
Eats by mouth	86	75	87
Eats alone	10	15	39

the same time, parents acknowledged that there were significant financial sacrifices and that their children experienced more pain than other children. Most parents reported that their family was strengthened since the birth, and often the death, of a child with T13 or 18. Parental decision-making was not homogeneous and reported outcomes were diverse, even in this cohort. Most parents in this cohort did not choose full interventions for their child. About one-third of the children whose parents chose a plan of comfort care survived beyond 1 year. A similar proportion of children whose parents chose a plan of full interventions died by the age of 3 months. When full interventions were chosen, similar proportions with trisomy 13 and trisomy 18 survived more than 1 year. It appears that interventions were effective in prolonging life of some children but were ineffective for others. Parents who become involved in social networks are likely to gain knowledge of a diverse range of choices and outcomes. Our results suggest that there are many areas in which the parental experience of having a child with T13-18 differs profoundly from the “conventional” view within the medical community. Recently, many articles have been published pertaining to the ethical and medical management of children with T13-18.<sup>25–33</sup> The quality of life of the child living with T13-18 is often described as a justification for not providing interventions for these diagnoses. For example, a commentary written by Catlin<sup>31</sup> acknowledged that interventions might prolong life, but “System by system [children with T-18] could undergo interventions; to my knowledge, the infant-level of intelligence would not change.” Some authors describe interventions for these children as going against their best interests because of their unbearable life.<sup>28,30,32–34</sup> As an illustration, Kopelman<sup>33</sup> suggested that “most adults would not want to prolong children’s lives with life-saving

intervention if, like baby T (with T13), they faced an existence of severe and intractable pain.”

Many articles point to the negative effects these children have on families, siblings, parents, marriages, finances, and so forth, without any data to support these claims.<sup>27,29–33</sup> The parents in this survey heard many of these predictions from their health care providers. Parents of children with variant (as opposed to full) T13-18 were provided with similar predictions despite the major heterogeneity of variant T13-18.<sup>8</sup> These predictions did not turn out to be true.

This study has some limitations. As noted earlier, this is not a representative sample of children born with T13-18. We have no data on women who chose to terminate their pregnancy nor data on couples who experience a fetal loss. Further, these are self-reported questionnaires with their inherent biases. Despite these limitations, because of our high response rate and large sample size, we are confident that our data provide a good representation of the quality of life and outcome of this community of parents and their children. This community of parents likely influences parents with a new T13-18 diagnosis.

Such data are critical to address the complex ethical issues that are increasingly present in the medical literature. A recent publication demonstrated that 44% of neonatologists would be willing to initiate resuscitation for a neonate with T18.<sup>26</sup> The authors state that: “There was universal consensus that T18 was a lethal anomaly [...] We speculate that support for the best-interest standard for neonates is diminishing in favor of ceding without question to parental autonomy [...] some neonatologists have an ethics of abdication.”<sup>26</sup>

This ethical analysis is incomplete without evidence of the parents’ experience. Quality of life and best interest considerations are essentially subjective. Health

care providers and parents frequently have different views on “a good quality of life.”<sup>35,36</sup>

Some parents would rather have a child with extremely severe disabilities than a dead child, more than many physicians.<sup>37</sup> We acknowledge that most women choose to terminate a pregnancy with T13-18 and that this decision may also reflect the values of many physicians as well. The broader social implication of decisions to terminate or intervene are beyond the scope of this article; our focus here is primarily to include the perspectives of those families who participate in social networks. Parents of children newly diagnosed with T13-18 who become integrated with social networks may acquire views, hopes, and expectations that are incongruous with those held by some of the clinicians they will encounter. Providers should be aware of the experiences of those families represented in this article. When parents request medical interventions, it may be because of what they have learned in their social networks.

## APPENDIX

### English-Language Internet-Based Parental Support Groups Dedicated to T13-18

Facebook groups:

- Trisomy 13-Patau Syndrome
- the Trisomy 18/13 Journey
- SOFT UK Trisomy 13/18
- Faces of trisomy
- Trisomy 18 mummies
- Living with trisomy 13
- Support Organization for Trisomy Patau Syndrome NEWS

Online groups:

- Support for families of babies with Trisomy 13, [www.trisomy18support.org](http://www.trisomy18support.org)
- Patau’s syndrome, <http://trisomy13-patausyndrome.blogspot.ca/>
- [www.noahsneverendingrainbow.org](http://www.noahsneverendingrainbow.org)

www.benotafraid.net  
www.trisomy.org  
www.leona-ev.de (Europe)

www.soft.org.uk  
www.trisomyonline.org  
www.softireland.com/

www.hopefortrisomy13and18.org  
www.prenatalpartnersforlife.org  
www.livingwithtrisomy13.org

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