

VIEWPOINT ARTICLE

# Medical interventions for children with trisomy 13 and trisomy 18: what is the value of a short disabled life?

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## ABSTRACT

Children with trisomy 13 and trisomy 18 (T13 or T18) have low survival rates, and survivors have significant disabilities. Life saving interventions (LSIs) are generally not recommended by many healthcare providers (HCPs). After a diagnosis of T13 or T18, many parents chose termination of pregnancy or comfort care at birth, but others consider treatment to prolong the lives of their children. While LSIs may be effective at prolonging the life of some children, the quality of life of survivors and the possible burden on the family may be considered negatively by HCP, which may lead to conflicts with families. Resource allocation considerations are often invoked to withhold LSI for T13 or T18 even though they are seldom mentioned for older patients with comparable outcomes.

**Conclusion:** We should strive to improve communication with parents by 1. Investigating these conditions further to be able to better inform parents and 2. Providing balanced information for families and personalised care for each child.

We have read with great interest the powerful article written by Thiele et al. (1) in this issue of Acta Paediatrica. In this article, three mothers relate their experience after a diagnosis of trisomy 13 or trisomy 18 (T13 or T18), two common life-limiting conditions. Their children had different life experiences: Liam died *in utero*, Evy-Kristine in her first week of life after life sustaining interventions were withdrawn in the neonatal intensive care unit, and Annie after a do not resuscitate order when she was admitted to the intensive care unit from home. Each family experienced similar challenges with the healthcare providers (HCPs). These families had made the choice to have and to love their severely disabled child, even if only for a while. They recount

their battles with healthcare providers who seemed to assume universal futility of life saving interventions (LSIs) and who had entrenched attitudes about the value of their children's lives. They experienced conflicts at a time when they could have focussed on making the best of the tragic truncation of their dreams for their child and on provision for that child of the best possible life, however short.

## THE CHANGING FACE OF DEATH AND DYING IN MODERN MEDICINE

Technological progress and clinical knowledge have increased the limits of what is possible in medicine and enable many children to survive or prolong their lives. However, life-threatening conditions often lead to complex decision-making involving withholding or withdrawal of LSIs.

Decisions on when to start, withhold or withdraw LSIs in critically ill children are among the most difficult

## Abbreviations

HCPs, HealthCare Providers; ICU, Intensive care Unit; LSIs, Life sustaining interventions; NICU, Neonatal intensive care unit.

decisions in paediatric practice. These decisions are fraught with ethical dilemmas, for example deciding whether withholding LSIs for a child with T13 or T18 (early death) is preferable to uncertain survival with disability after the burden of LSIs. The interpretation of risks, benefits and outcomes varies between individuals with different values. In this article, we will discuss decisions about LSI in the context of children with trisomy 13 and trisomy 18.

### TRISOMY 13 AND TRISOMY 18

Trisomy 13 and trisomy 18 are the second and third most frequent chromosomal anomalies after Down syndrome and are frequently referred to as being 'lethal' disorders because of their serious outcomes (2). The risk of foetal loss during a pregnancy with T13 or T18 is high (3), children with T13 or T18 have survival rates beyond 1 year of 6–12% and have profound neurodevelopmental disabilities when they survive (4,5). The American Academy of Pediatrics recommends against newborn resuscitation for these conditions (6). The 2010 American Heart Association guidelines make similar recommendations (7). A significant number of pregnancy terminations occur after a prenatal diagnosis of T13 or T18 (8). Nonetheless, some women continue their pregnancy and may request LSIs for their child, which may cause tensions with HCP who may disagree.

### ARE MEDICAL INTERVENTIONS BENEFICIAL FOR CHILDREN WITH TRISOMY 13 AND TRISOMY 18?

These serious life-limiting conditions are not homogeneous, as illustrated by the stories of Liam, Annie and Evy-Kristine. Many children suffer from severe anomalies, including holoprosencephaly and/or complex cardiac malformations and die before, during or shortly after birth. However, others have no or fewer severe anomalies and can be discharged home with minimal medical interventions, such as tube feeds.

A recent publication described the experience and choices of a large cohort of parents (9). Parental decision-making regarding LSIs was heterogeneous: the majority chose comfort care for their child, yet some opted for LSIs (9). In that same study, reported outcomes were diverse: some children died despite LSI, others survived with LSI and some survived for more than 1 year with palliative care (9). A 12-year review of hospitalisations for American children with T13 or T18 revealed that more interventions are performed for these conditions than previously thought and concluded 'universal application of the term "lethal" to the diagnoses of trisomy 13 and trisomy 18 is not appropriate.' (10) In Japan, the approach to these conditions has been different for many years. The 1-year survival rates have been reported to be as high as 56% in some Japanese studies (11,12).

In a process characterised as informed consent, HCPs are taught to inform parents in an unbiased fashion, present them the possible interventions and outcomes,

answer questions and then ask parents to choose appropriate treatment options. These variations of practice raise an interesting question about informed consent. What kind of survival statistics should we give parents? Survival rates without LSIs or survival in countries where LSIs are more commonly used? Policy statements and the opinions of HCP will have a direct impact on the information parents receive and the survival of their children. It is often said in clinical ethics that good ethics starts with good facts. With these conditions, we can observe that values influence medical statistics (13). Life sustaining interventions can significantly prolong the life of *some* children with T13 or T18, but may harm others. Of importance, the quality of life of survivors and the impact these children have on families and our healthcare system need to be considered.

### A LIFE NOT WORTH LIVING? CONTRAST BETWEEN PARENTAL AND PROVIDERS OPINIONS

#### Quality of life arguments

Arguments about the balancing of treatment options are commonly expressed in terms of quality of life, a legitimate tool in the balancing of the burden of interventions against the benefits gained by interventions. In the case of T13 or T18, professional associations have made the value judgement that prolonging the lives of these children is not recommended, which is to say that these lives are not worth living. HCPs tend to judge disability more harshly than parents and underestimate the quality of life of disabled children (14). They are more likely to think that being severely disabled is worse than being dead, unlike parents (15).

Many authors have stated that children with T13 or T18 have a negative impact on their families, without any data to support their claims (16). In 2012, a study examined the experience of parents who had children with T13 or T18 (9). Three hundred and thirty-two parents reported being told by HCPs that their child was incompatible with life (87%), would live a life of suffering (57%), would be a vegetable (50%) or would ruin their couple or family (23%). 50% of parents reported that taking care of a disabled child is/was harder than they expected and that they had to make significant financial sacrifices. Despite their severe disabilities, 97% report they can communicate with their child to understand their needs and described their child as a happy child. Parents reported these children enriched their family and their couple irrespective of the length of their lives (9). Some authors have determined that a minimal requirement of an acceptable quality of life is the ability to interact with loved ones and to express and perceive emotion. This can be achieved at some level by many children with T13 or T18 (9,17).

#### Best interests arguments

Ethically and legally, decision-making for children should be based on an evaluation of what is in their best interests. Estimating the best interests of a child with T13 or T18 is

complex. HCPs often use traditional indicators of benefit in modern medicine, such as survival and disability, but many other value judgements affect their decisions. HCPs often do not follow the best interest standard for life and death decisions in critically ill children, particularly for neonates (18–20). For example, HCPs are more likely to think LSIs are in a critically ill baby's best interest when birth happens after *in vitro* fertilisation to 'older' parents (19). HCPs are more frequently willing to withhold LSIs from sick neonates than from older children or adults with similar or even much worse prognoses (18,20). It has also been demonstrated that some HCPs with the greatest fear of their own death are more likely to actively manage the dying process of their patients, perhaps even accelerating their deaths (21). Such unacknowledged and unexamined biases affect the behaviour of HCPs but rarely, if ever, feature in discussions with families.

### Futility arguments

Many position statements (6,7), hospital policies and authors (16,22,23) consider that LSIs for children with T13 or T18 are futile. But futility can be defined in quantitative or qualitative terms. Quantitative futility implies that LSIs 'do not work' or that LSIs may have more than 0% success rate, but 'success is ... so unlikely that its exact probability is often incalculable' (24). Yet, 1 year survival with a diagnosis of T13 or T18 is between 6 and 50%, which does not satisfy the definition of quantitative futility. Qualitative futility generally means that LSIs are 'not worth it'. This subjective consideration of whether the intervention reaches desirable goals may be evaluated by HCPs or patients. Schneiderman defines futility as 'the unacceptable likelihood of achieving an effect that the patient has the capacity to appreciate as a benefit' (25). What is unacceptable? What is a benefit? Who assesses the goals of care? When futility is invoked in children with T13 or T18, it is often qualitative futility, value-laden futility ('not worth it').

### RESOURCE ALLOCATION AND THE IMPACT OF THESE DECISIONS ON SOCIETY

Some authors use the just distribution of resources as a reason for being cautious in giving LSIs to children with T13 or T18. In the financially constrained environment of modern healthcare, resource allocation is a legitimate and important concern. We need to consider what bothers us about the costs of LSIs for children with T13 or T18 the quantity or the quality of their lives? The fact that many children with T13 or T18 may die despite LSIs and utilise precious resources is a fact. But this outcome is not uncommon in modern intensive care units (ICUs). Many older patients die in the intensive care units (ICUs) after LSIs, such as children with trauma and devastating cancers, adults with strokes, cardiovascular events, brain cancer, etc. In fact, 29% of adult ICU bed days are used by patients who die, compared with 8% in the neonatal intensive care units (NICU) (26). What may bother some is that these children

may in fact survive with LSIs, utilising additional resources during their short lives, or that for these outcomes, the investment is seen as 'not worth it'. Interestingly, it is common in our medical system to use precious resources to prolong the lives of older patients needing total care. Many of these patients have outcomes comparable to children with T13 or T18, such as patients with severe dementia, neuromuscular disorders or severe disabilities following an adverse event.

In many industrialised countries, up to 25% of health expenditure is devoted to the care of individuals in their last 6 months of life. It is unknown whether patients and families consider these 6 months being worth these resources. It may be that the public would decide that utilisation of resources to prolong the lives of disabled patients for a short time is not wise. If this were to be the case, withholding LSIs from children with T13 or T18 would not yield significant savings for many reasons. These conditions are rare, the majority of parents decide to terminate the pregnancy, the rate of foetal loss is high and when children are born alive, the majority of parents opt for comfort care. On the other hand, head trauma, strokes, brain cancer, neurodegenerative diseases and dementia are common. If LSIs were withheld from patients who have outcomes comparable to children with T13 or T18, significant resources could be saved. It is likely that many hospitals could be closed.

### Neonates compared with older patients

When making life and death decisions, HCPs are more likely to prioritise the needs of older children and adults over those of neonates, despite knowing that many of them have similar or worse outcomes (27). It seems that investing considerable resources at the end of a productive ('normal') life is considered by some to have value. Adding 6 months to the disabled life of a 7 year old is preferred to adding 6 months to the life of a neonate (18,20,27).

Some may argue that resources should be devoted to those with the most to gain and perhaps the greatest potential to repay the investment. Why is such treatment of our elderly so unquestioned, when they are nearing or past the end of 'economically productive' life? It may have something to do with our ability to empathise with those who are in a position in which we can see ourselves in a few years. It could be because they have already contributed to the economy; they have a right to a share of our public resources. Some neonates with T13 or T18 will die in the NICU despite LSIs and never go home to their families, spending all their lives on machines in the hospital. This may be seen as qualitative medical futility by many HCPs and parents. This is rarely the case for older patients. For example, an ageing patient may spend 1% of her life in an intensive care dependent upon machines.

Such decisions also, however, probably reflect an age-old regard for the elderly as an important part of our lives, with an importance beyond their value as economic units or the wisdom they may give – our support for them ensures that

they stay in our lives, which are enriched by their presence and may perhaps also have value as a symbol of the fact that we are able to value things other than economic productivity, symbols of an enriched humanity, perhaps even a 'morally enhanced' humanity (28).

### **IN WHAT KIND OF SOCIETY DO WE WANT TO LIVE?**

#### **Fragile short lives as moral enhancers**

In our opinion, fragile neonates with short lives can enrich society. We live in a society that is at often centred on goals, excellence, performance and perfection. While these have value they can impoverish if taken to extremes. Many parents report that having a child with a life-threatening condition was difficult, but that it also enriched their lives and had a positive effect on siblings (9). They learned to love and expect nothing in return, they learned that imperfection does not mean inferior, they learned to not take life for granted, they learned to celebrate every day as if it was the last. While some authors propose moral enhancement through medications (28), we have observed that these short fragile lives morally enhance society by having a positive impact on those who love them.

#### **The importance of the diversity of lives and choices**

Competent adults will approach life-threatening illnesses very differently. For example, some adults with Amyotrophic Lateral Sclerosis, a neurodegenerative disorder, decide that comfort care is superior to interventions when they can no longer eat and breathe on their own. Others elect to have a gastrostomy, a tracheostomy and a respirator to prolong their lives, such as Nobel Prize winner Stephen Hawking. Different parents will also take very different decisions after a diagnosis of T13 or T18. We should give thought to the greater richness of a community in which a variety of lives and ways of being can flourish, in which the simple mutual love of parent and child can suffice in its own right but can also perhaps teach us about the need at times to focus on simpler things. The presence of open, diverse communication models around such difficult issues also enriches us, as it speaks powerfully to a respect for the diversity of opinion and choice that is so central to most modern societies.

### **STRIVING TOWARDS BALANCED INFORMATION AND PERSONALISED CARE**

#### **Humility and curiosity: further research is needed to determine factors associated with longer survival**

By declaring that T13 or T18 are universally lethal conditions with 'unacceptable outcomes' for which LSIs are not indicated (6,7,16,22,23), HCPs have harmed this population. Indeed, while some children have many anomalies and may be harmed by LSIs, others survive with LSIs and go home to families who love them (9). We have failed to scientifically and rigorously investigate these conditions the way other conditions are investigated. Some medical interventions may be associated with a

longer life (such as tube feeds or a gastrostomy). Some characteristics of affected children may predict a shorter life, despite LSIs (such as holoprosencephaly, growth restriction or a complex cardiac anomaly). Cardiac surgery for some anomalies may improve the quality of life of some children. By stating that LSIs are beneficial to some children with T13 or T18, we can admit our ignorance and start investigating these important topics in a rigorous manner. This can only be carried out with curiosity about families who have lived with these children (1,9).

#### **Balanced approach, information and personalised care**

While LSIs and invasive surgeries may harm some children by hastening death while imposing a significant burden of care, the lack of LSIs for all children with T13 or T18 may also harm those who may have benefited from these interventions. Further rigorous research about these conditions will enable us to have a balanced approach and avoid extremes, understanding that navigation between doing 'too much' or 'too little' is often complex and requires an open mind.

Experience shows that the majority choose termination of pregnancy after a diagnosis of T13 or T18. This is an option that must be discussed and is appropriate for many parents. It is, however, seen and presented as normative by many counsellors, and parents commonly report a pressure to choose this option. Parents who do not take the usual path commonly report incomprehension, negativity and sometimes lack of support.

Parents who experience a prenatal diagnosis of T13 or T18 may decide to continue their pregnancy for a number of reasons. HCPs need to understand parental perspectives and realise that while T13 or T18 cannot be 'cured', the children have value and meaning to their parents regardless of life span and disability (9). HCPs can provide personalised and balanced information for these families (29). Informing parents about the short survival and severe disabilities is important, as well as informing them about the experience of families who were faced with the same diagnoses (9). Taking care of a disabled child is difficult and financially challenging, yet families describe these children enriched their families and often have no regrets. Information can be personalised by knowing the name of a child/foetus, by pointing out which organs are malformed and which are not, by asking parents what their hopes are for their child. Personalising care can also mean informing parents that although survival statistics are poor for these conditions, that it is their child – with his particular features – in their family they will consider. To reach an optimal life trajectory for each child in each family should be the goal (29).

#### **Words are important**

Koogler and colleagues have stated that lethal language leads to lethal decisions (2). Trisomy 13 and trisomy 18 are not lethal conditions. They are life-limiting conditions. The use of language such as 'futile' or 'lethal' in counselling

often proves to be a self-fulfilling prophecy if it denies LSIs for some children who might have benefited them (30). Parents of children with T13 or T18 find some words offensive (9), such as 'doing everything', 'nothing we can do', 'no hope', 'lethal', 'incompatible with life', 'futile', 'vegetable', 'this child will cause harm to (you, your kids, your job, your finances, your couple)', 'you can have another one', 'we do not take these kids in our NICU'. Parents particularly disliked HCPs who did not call their child by name but by the condition (T13 or T18; Edwards) or by their anomalies (holoprosencephaly) (9).

We have observed many HCPs saying 'these parents refused termination' when speaking about T13 or T18, instead of saying 'they chose to continue the pregnancy after the diagnosis'. Although these both imply there was no termination of pregnancy, they do not carry the same message about the parents.

Hope is important to parents. When parents decide to have a child, they hope for a healthy pregnancy and a strong child. After a diagnosis of T13 or T18 parents' hopes change, parents "recalibrate" their hope. Some parents hope they will meet their child alive (1). They may hope their child simply survives for the longest time possible or that they can at least take their child home. For some parents, there is still hope that they can be there for their child, that they can live without regret and remorse and that they can heal after the death of their child.

There is always something we can do (1,9,29). For some extremely fragile children with several major malformation and/or low birth weight, LSIs can indeed be quantitatively futile, but we can always be there to support families in these tragic moments. We can guarantee that we will do everything in our power to treat any pain of discomfort their child may have. We can tell parents that the most important thing is that this child has parents who care and love him. That we also hope that they will meet their child and be a family for a while. While it is important not to give unrealistic hopes to parents, we can assure them that we will do everything for their child to have the best life possible.

After a new diagnosis, parents often seek information and support to make important decisions. The presence of disability may be perceived as leading to a devaluation of a loved child by the HCP, defining the child as of lesser value by virtue of their genetic diagnosis. Should this continue, it commonly undermines trust in the carer, leaving the family even more isolated. For families facing end of life decisions, trust in HCP is critical. A lack of trust may lead parents to refuse reasonable recommendations made by HCPs. Language as well as attitudes some HCPs have about children with T13 or T18 may also lead some parents to feel their child has no value to providers, to trust no one and 'fight' for their child's life, while HCPs may tell them that there is 'nothing we can do', they may demand that 'everything be provided' even for a child who has multiple severe anomalies that require many invasive interventions. This is not uncommonly a consequence of a 'closed' process or total lack of trust in

HCPs; parents may be forced into a position in which they must fight to obtain interventions for their child, leading to an entrenchment in positions and a cessation of dialogue. An attitude and language of universal futility and lethality for these conditions has unfortunately created many conflicts.

## CONCLUSION

We now have the ability to save and prolong lives, but in doing so, we have a significant impact on the quantity and quality of life of children and their families. Life-threatening conditions such as T13 or T18 are not only diseases of children but they are diseases of families, mothers, siblings and affect the society in which these children live. For physicians who counsel parents with a new diagnosis of T13 or T18, life and death decisions have become routine. For parents, it is far from routine. A life-limiting diagnosis such as T13 or T18 is a bomb in parents' lives. The decisions parents make for their baby and every detail of the events surrounding their child's death will change their lives forever. Medical developments have changed the way we respond to life-threatening illnesses; not only as physicians, but also as a society. We need to respond adequately to these new challenges. We have a critical role and opportunity to help families heal. When we truly individualise and personalise our approach, we can contribute to the well-being of the family and child.

## CONFLICT OF INTEREST

Both authors have no conflict of interest.

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