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The Two Clocks: Diagnosis, Prognosis, Relational Time, and Crip Time Following a Prenatal Diagnosis of Trisomy 18

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Abstract

Prenatal diagnosis of Trisomy 18 is commonly accompanied by clinical counselling focused on fetal loss, neonatal mortality, congenital anomalies, and anticipated disability. Such information is necessary for informed decision-making. However, families who continue pregnancies affected by Trisomy 18 often describe a second narrative in which time is understood not only through prognosis but through attachment, belonging, care, memory-making, and love. This reflective medical humanities paper examines these two temporal frameworks: the clinical clock and the relational clock. Drawing on parental-experience literature, perinatal palliative care, disability studies, and the concept of "crip time," it argues that ethical prenatal counselling requires integrating prognostic realism with recognition of relational meaning. Medicine measures duration and risk; families also experience presence, identity, and enduring bonds. Both forms of time should be present in compassionate prenatal counselling.

Keywords: Trisomy 18, Prenatal Diagnosis, Perinatal Palliative Care, Disability Studies, Crip Time, Medical Humanities, Family-Centered Care, Parental Experience

The clinical clock and the relational clock

Figure 1: The Two Clocks Framework. The Clinical Clock Measures Prognosis, Risk, Survival, and Anticipated Medical Complexity. The relational clock measures presence, attachment, care, memory-making, belonging, and continuing bonds. Compassionate prenatal counselling requires both forms of time to be held together rather than allowing either to erase the other

1. Introduction

On 21 June 2023, a family received a prenatal diagnosis of Trisomy 18 for their unborn son, Josea. This paper is written from the standpoint of an observer and friend of the family, rather than from the position of a treating clinician or researcher reporting original participant data. That position matters: the reflections offered here arise from witness, proximity, and care, and are interpreted through published medical, ethical, parental-experience, palliative-care, and disability-studies literature. Trisomy 18 is a chromosomal condition associated with multiple congenital anomalies, high fetal

and neonatal mortality, and significant developmental disability among surviving children [1,2]. The diagnosis introduced not only medical information but also a particular way of understanding time. In the consultation room, the family encountered a clinical narrative shaped by risk, prognosis, survival, and anticipated suffering [1-3]. At the same time, through the stories of other families, they encountered a different narrative: one in which time was understood through love, attachment, presence, care, grief, joy, and belonging [4,5]. This paper explores these two forms of time through the metaphor of two clocks. The first is the clinical clock, which measures time through prognosis and risk. The second is the relational clock, which measures time through relationship, meaning, and continuing bonds. This distinction does not reject medical knowledge. Rather, it shows that prognosis alone cannot fully describe the lived experience of families facing a life-limiting prenatal diagnosis [6,7].

2. The Clinical Clock: Time as Prognosis and Risk

Modern medicine necessarily operates through measurable time. Prognosis depends on gestational age, survival rates, mortality curves, intervention thresholds, and anticipated clinical outcomes. In Trisomy 18, this framework is clinically important because families need accurate information about fetal loss, neonatal death, congenital anomalies, and the possible burdens of intensive treatment [1-3]. Within this clinical clock, pregnancy may be described in relation to escalating fetal risk, birth in terms of survival probability, and postnatal life through anticipated suffering, medical complexity, and possible death[1,2]. This clinical framing is not inherently wrong. Healthcare professionals have an ethical duty to communicate serious prognosis clearly. Families cannot make informed decisions without understanding the gravity of the condition [6-8]. However, problems may arise when prognosis becomes more than information and begins to define the meaning of the child's life [4,5]. Historically, Trisomy 18 has often been described using terms such as "lethal" or "incompatible with life [2,8]." Such language may reflect the seriousness of the diagnosis, but it can also unintentionally close down discussion, reduce the child to the diagnosis, and imply that continued pregnancy or postnatal care is irrational [4,5,8]. More recent ethical and paediatric guidance has moved away from universal diagnosis-based assumptions and towards individualised counselling, shared decision-making, and family-centred care [6-8]. Thus, the clinical clock is necessary but incomplete. It can tell families what may happen medically. It cannot, by itself, tell them what the time will mean.

2.1. The Relational Clock: Time as Presence and Belonging

Families who continue pregnancies affected by Trisomy 18 often describe time in a different way. Rather than seeing time only as a countdown to loss, they may experience it as an opportunity for relationship [4,5]. In parental-experience studies, families frequently report that the child was experienced not merely as a diagnosis but as a son or daughter, a sibling, and a member of the family. Their hopes were often not based on cure or long survival, but on the possibility of meeting the child, naming the child, holding the child, providing care, and creating memories [4,9]. In this relational clock, time is valued not only by length. A brief life may still be meaningful. A medically complex life may still be loved. A child who never reaches conventional milestones may still profoundly shape family identity. The relational clock therefore resists a simple binary between suffering and meaning. It allows grief and love to exist in the same space.

2.2. Crip Time and the Reframing of Normal Time

Disability studies provides a useful framework for interpreting this second form of time. The concept of "crip time" describes forms of time that do not conform to dominant expectations of speed, productivity, independence, and linear progress [10,11]. Crip time is not failed time. It is reconfigured time. It recognises that disabled, medically complex, and care-dependent lives may unfold according to different rhythms [10-12]. These rhythms may include hospital appointments, feeding routines, breathing support, rest, waiting, uncertainty, and altered developmental expectations [9-12]. For families caring for children with life-limiting or medically complex conditions, time may become slower, more interrupted, and more dependent on care. Yet this slowness is not necessarily wasted. It may create a different form of attentiveness, intimacy, and presence. Recognising crip time invites clinicians to move beyond linear expectations of outcome and to support forms of care that prioritise presence, relationship, and attentiveness as well as clinical management. This challenges social assumptions that human value is tied to independence, economic productivity, or conventional developmental achievement [10-13]. Within the relational clock, Josea's value does not depend on what he can produce, achieve, or become. His value rests in who he is and in the relationships of which he is part. As introduced above, crip time provides a further lens for understanding the relational clock through the concept of "crip time." Crip time challenges dominant assumptions about how time "should" function within medicine and society. Conventional time is often linear, future-oriented, and structured around milestones: growth, independence, productivity, and progression. Within this framework, value is implicitly attached to speed, efficiency, and the achievement of expected developmental or functional outcomes.

Crip time disrupts this model. It recognises that disabled and medically complex lives do not follow uniform or predictable timelines. Rather than being organised around acceleration and progress, such lives may be shaped by unpredictability, interruption, dependency, repetition, and care. Time may be punctuated by hospitalisations, waiting, recovery, setbacks, and adaptation. Milestones may arrive differently—or not at all. What appears, within a conventional framework, as delay or deviation may instead represent a fundamentally different temporal structure. Importantly, crip time is not simply "slower time" or "impaired time." It is a reconfiguration of time itself. It challenges the assumption that value depends on forward movement toward independence or productivity. Instead, it creates space for forms of life and relationship in which presence, attentiveness, vulnerability, and interdependence are central. In this sense, crip time unsettles the hierarchy that places independence above dependence, and productivity above care. For families navigating a prenatal

diagnosis of Trisomy 18, crip time may begin even before birth. The anticipated life of the child is not imagined as a trajectory toward conventional adulthood, but as a life that may be brief, medically complex, and deeply relational.

Time may be experienced less as a linear pathway and more as a series of intensely meaningful moments: ultrasound appointments, birth planning, holding the child, shared routines, and, potentially, end-of-life care. These moments may be few in number yet profound in significance. Crip time also reframes uncertainty. In the clinical clock, uncertainty is often translated into probabilistic risk and anticipated outcomes. In crip time, uncertainty becomes part of lived experience—something inhabited rather than resolved. Families may come to dwell within uncertainty, holding hope, fear, grief, and love simultaneously rather than moving sequentially from one stage to another. This temporal openness can allow meaning to emerge even in the absence of predictable outcomes. For clinicians, recognising crip time has important implications. It invites a shift away from framing care solely in terms of restoring or approximating "normal" timelines, and towards supporting the lived temporalities of patients and families. This may involve valuing time spent in bonding, comfort, and presence as clinically meaningful, rather than secondary to intervention. It may also require flexibility in care planning, allowing for non-linear pathways and goals that are defined by families rather than by standard developmental expectations. Crip time therefore deepens the relational clock. It shows that relational meaning is not simply added to clinical time but is grounded in an alternative understanding of time itself. Within this framework, a life does not need to be long, progressive, or productive to be meaningful. It needs only to be lived in relationship. Time, in this sense, is not measured solely by duration, but by depth, connection, and significance.

3. Why this Works for your Paper

This expansion:

- strengthens the theoretical depth (useful for reviewers)
- connects crip time more explicitly to clinical implications
- integrates smoothly with your existing "two clocks" framework
- avoids over-technical language while remaining scholarly

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3.1. Beyond Productivity: Human Worth and Medical Complexity

A major ethical tension in prenatal counselling concerns how human worth is imagined. Contemporary societies often value autonomy, efficiency, independence, and productivity [10-13]. These values can shape clinical and social attitudes towards disability, sometimes leading to the assumption that severe disability necessarily means poor quality of life [8,10,13]. Parental narratives challenge this assumption. Families may acknowledge medical complexity while still describing the child's life as meaningful and the relationship as valuable [4,5]. They do not necessarily deny suffering, rather, they reject the conclusion that suffering removes worth [4,5,9]. This distinction is important for clinical practice. To describe a condition as serious is appropriate. To assume that a life affected by serious disability is therefore without value is not [6-8]. The role of healthcare professionals is not to impose either optimism or pessimism. It is to provide accurate information, recognise uncertainty, respect parental values, and support families through decision-making [6-9].

3.2. Perinatal Palliative Care: Holding Both Clocks Together

Perinatal palliative care offers a clinical model that can hold both clocks together. It recognises the seriousness of the diagnosis while also supporting family goals such as birth planning, comfort care, memory-making, bonding, spiritual care, and bereavement support [9,14]. This model does not require families to deny prognosis. Instead, it allows them to live meaningfully within prognosis. It creates space for parents to meet their child, make decisions consistent with their values, and receive coordinated support before and after birth. Perinatal palliative care therefore reframes time. Time is not only the interval before death. It is also the space in which relationship, care, memory, and belonging may occur.

3.3. Continuing Bonds Beyond Biological Time

The difference between the two clocks becomes especially clear after death. Clinical time ends when biological life ends. Survival statistics reach their endpoint. Medical charts close [1,2]. Relational time does not end in the same way. Bereavement literature recognises that many parents maintain continuing bonds with children who have died [15]. These bonds may be expressed through memory, ritual, naming, storytelling, photographs, anniversaries, spiritual belief, and ongoing family identity. In this framework, Josea's time is not erased if his physical life is brief. His life continues to shape those who love him. The relationship remains part of the family's story. This is one of the strongest challenges to the idea that such time is wasted. If a child is loved, known, named, held, and remembered, then the time has relational consequence. It has formed the family. It has become part of them.

4. Discussion

The metaphor of the two clocks helps explain why prenatal counselling for Trisomy 18 can feel so different to clinicians and families. Clinicians may focus on prognosis because they are trained to anticipate risk and prevent suffering. Families may focus on relationship because they are already encountering the child as their child [4-9]. These perspectives need not be enemies. The clinical clock provides necessary realism. The relational clock provides human meaning. Ethical care requires both [6-9]. When the clinical clock dominates, families may feel pressured, dismissed, or deprived of hope [4,5]. When the relational clock dominates without clinical realism, families may be left unprepared for suffering, medical complexity, or death [6-9]. A balanced approach recognises that families need accurate prognostic information and permission to love their child within whatever time is given [6-9,14]. This paper is limited by its reflective and interpretive nature. It does not report original empirical research, and not all families

will experience relational time in the same way. Cultural, spiritual, social, and clinical contexts may shape how parents understand prognosis, disability, care, loss, and meaning.

4.1. Implications for Clinical Practice

First, clinicians should present prognosis clearly without implying that prognosis determines the value of the child's life [1,2,6-8].
Second, counselling should avoid language that prematurely closes moral and clinical discussion, including blanket phrases such as "incompatible with life [2,6-8]."

Third, families should be offered both medical outcome data and access to family-experience literature, peer support, or parental narratives where appropriate [4,5].

Fourth, perinatal palliative care should be presented not as "doing nothing" but as an active model of care focused on comfort, dignity, bonding, memory-making, and family support [9,14].
Fifth, clinicians should recognise that parents may define meaningful time differently from healthcare professionals [4,5,10-12].

Finally, bereavement care should acknowledge continuing bonds and support families in carrying the child's memory as part of ongoing family life [15].

5. Conclusion

A prenatal diagnosis of Trisomy 18 introduces families to two clocks. One measures risk, prognosis, and duration. The other measures presence, belonging, and love.
Medicine must speak truthfully about the first clock. Compassionate care must also make room for the second.
The clinical clock asks, "How long might this life last?"
The relational clock asks, "What meaning can this life hold?"
Both questions matter. A humane model of prenatal counselling must be able to ask both.

Declarations

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Author Positionality: The author writes as an observer and friend of the family, not as a treating clinician or as a direct participant in clinical decision-making. The paper is offered as a reflective medical humanities analysis informed by proximity, care, and witness, while drawing on published clinical, ethical, parental-experience, palliative-care, and disability-studies literature.

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