



Infertility, reproductive timing and ‘cure’ in families affected by Turner Syndrome

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ARTICLE INFO

Handling Editor: Medical Sociology Office

Keywords:

Turner Syndrome
Infertility
Chromosome disorder
Reproductive timing
Futurity
Imaginations

ABSTRACT

This article discusses the influence of a chromosome condition affecting women’s reproductive capacity, Turner Syndrome (TS), on affected women’s social timing, examining the strategic decisions that are made within families in relation to reproduction, to navigate these disruptions. Based on photo elicitation interviews with 19 women with TS and 11 mothers of girls with TS in the UK, it presents findings from an under-researched topic, TS and reproductive choices.

In a social context where motherhood is not only desirable, but expected (Suppes, 2020), the social imaginary of infertility anticipates a future of unhappiness and rejection, an undesirable condition that should be avoided. Accordingly, mothers of girls with TS often expect that their daughter will want to have children. Infertility diagnosed in childhood has a distinctive impact on reproductive timing, as future options may be anticipated for years. This article uses the concept of ‘crip time’ (Kafer, 2013) to explore how women with TS and mothers of girls with TS experience temporal misfitting based on a childhood diagnosis of infertility, and manage, resist and re-frame this to minimise stigma. The ‘curative imaginary’ (Kafer, 2013), a social norm where disabled people are expected to desire a cure for their condition, is used as an analogy for infertility, describing how mothers of girls with TS respond to social pressure to plan for their daughter’s reproductive future.

These findings may be useful both for families navigating childhood infertility and practitioners who support them. This article demonstrates the cross-disciplinary potential of applying disability studies concepts to the context of infertility and chronic illness, where concepts shed new light on the dimensions of timing and anticipation in this context, improving our understanding of the lived experience of women with TS, and how they view and use reproductive technologies.

1. Introduction

Timing is key to the social understanding of the life course. Social imaginaries relating to maternity express shared expectations of social timing by articulating the appropriate time and age when events such as puberty, onset of menarche, marriage, and conception, should take place. The normative social imaginary of a woman’s life course is that she desires motherhood and becomes a mother at a socially-accepted time of life (Hudson, 2019). By extension, a shared social understanding of the ‘right’ time also gives a shared understanding of the ‘wrong’ time. Conditions affecting girls’ and women’s reproductive capacity may challenge their ‘social timing’, that is, their ability to adhere to age-related shared expectations of achievement and progress through the life course.

This article examines how Turner Syndrome (TS), a spontaneous genetic disorder affecting women that usually causes infertility, disrupts

this anticipated temporal progression in ways that can be stigmatising. The associated experience of non-conformity with the social norms of timing across the life course can lead to a sense of being frequently ‘out of synch’ with peers. It considers how, in response to the belief that it is likely their daughter will want children, mothers of girls with TS explore family-building options that could enable their daughter to overcome or ‘cure’ infertility. TS has a significant impact on social timing throughout life; its most consistent characteristics are short height and reduced fertility or infertility. Girls tend to have delayed physical growth and delayed or absent puberty and menarche, signs which usually prompt a diagnosis in childhood (Gravholt et al., 2017). Slow growth is treated with growth hormone until puberty, and menarche is initiated with oestrogen. Most girls with TS are born with no ovaries, or their ovaries do not function by the time they reach puberty: only 5% of women with TS can conceive spontaneously (Mavridi et al., 2018). The most frequent age at diagnosis is 8, but TS may be diagnosed prenatally, and most

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<https://doi.org/10.1016/j.socscimed.2023.116005>

Received 27 February 2023; Received in revised form 14 May 2023; Accepted 1 June 2023

Available online 2 June 2023

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women are diagnosed by the age of 20 (Gravholt et al., 2017). In the general population, infertility is most often diagnosed in adulthood, when people begin trying to conceive; in women with TS, family-building decisions are often reached after living with the impact of the condition since childhood, anticipating infertility (and the possibility of a high-risk pregnancy) for years. Parents of girls diagnosed in childhood are advised to discuss the fertility implications early on (Bondy, 2007). As this article goes on to discuss, mothers may subsequently begin to anticipate, and consider how to address, their daughter's future infertility. As well as more conventional options, this can include intrafamilial donation using eggs from sisters, or maternal eggs, frozen while the mother is fertile, for her daughter's use in later life. Both options are time-sensitive; maternal egg freezing has been widely discussed in TS communities, but research on this topic is scarce. TS can also affect friendships and relationships: the associated neurocognitive profile includes, for a significant minority, later social and emotional development than peers and difficulties with social understanding (Wolstonecraft and Skuse 2019). Women with TS tend to form relationships and marry less frequently, and later, than average women (Gould et al., 2013). These factors significantly affect women's ability to comply with shared cultural expectations about the appropriate timing of life course events such as physical and emotional development, marriage and childbearing.

There is an extensive body of literature on the medical and psychosocial impact of TS, but very little on women's experience of living with TS. Even though medical technology has increased the reproductive options available, little qualitative research explores the reception of these technologies or how women and their families navigate these decisions. This article draws on data from a study of the way women make reproductive choices in the context of TS, involving both women with TS and mothers of girls with TS. It utilises concepts from disability studies scholarship to illustrate and analyse the way women make reproductive choices in the context of 'anticipatory biomedicine' (Bach and Krolokke, 2019), where people are expected to anticipate and act to avoid future health issues. It applies the concept of 'crip time' (Kafer, 2013) to the reproductive and developmental timing of TS, to show how families manage and attempt to normalise issues of timing. It looks at attitudes which view assisted reproduction as potentially 'curative' for infertility, where a cure is defined as one of several potential options that enable an infertile person to comply with social norms to have a family. The concept of the curative imaginary (Kafer, 2013) is used to examine the way in which normative expectations of reproductive timing, and imaginaries of mothering behaviour, can inform mothers' planning for their daughter's reproductive future. Contributions to the interdisciplinary dialogue between medical sociology and disability studies are sparse (Thomas, 2022); this paper shows how concepts from disability studies can illuminate the dimensions of timing, anticipation and resistance within a discussion about the interaction between fertility and chronic illness.

This paper extends the use of common reproductive imaginaries such as mandated maternity (Russo, 1976), showing how they combine with social norms of mothering (Faircloth and Gurtin, 2017) to apply pressure to mothers to consider ways to plan for their daughter's future reproductive choices.

2. TS and social timing

Social understandings of the way women's bodies work are underpinned by a "temporal logic" (Rimon-Zarfaty and Schweda, 2019) defining the right time for women to reproduce. Normative reproductive timing, based around the idea of the biological clock (Pasqualotto et al., 2008), defines the appropriate time to have a family, while 'procreative norms' (Wilkinson, 2020) characterise the normative setting as a heterosexual couple relationship. These norms are grounded in wider social imaginaries, based on shared social values, which express a shared idea of a normative life course; they enable people to anticipate their future

life trajectory. Imaginaries underpin social norms such as the motherhood mandate (Russo, 1976; Roseneil et al., 2020; Suppes, 2020), the expectation that every woman desires motherhood and will become a mother, and intensive mothering, the presumption that mothers are responsible for actively shaping their child's future (Faircloth and Gurtin, 2017). While fertility is valorised, infertility is usually stigmatised, and the future imaginary of childlessness is often presumed to be negative.

While social norms of relationships and family forms have become more fluid and diverse in recent years, in ways which arguably offer increased gender equality (Giddens, 1992), traditional gender inequities in intimate relationships persist, and may be exacerbated after a couple has children (Jamieson, 1999). Parenthood is still a normative social expectation for adults, while infertility is stigmatised (Greil, 1991; Sandelowski, 2016). In the UK, involuntary childlessness may be conflated with being childfree, leading others to assume that childless women are 'selfish', 'delaying' or 'not trying' (Bell, 2013, p290). This can be difficult to navigate, since women may not wish to disclose their circumstances, feeling that others may think of them as a failure (Letherby, 2002). In Pellatt's (2005) study, women with TS explicitly constructed infertility as a 'dis-ability' or a 'reproductive impairment' (Pellatt, 2005, p95), where the absence of ovarian function positioned them outside the normative narrative of womanhood, producing felt stigma that affected their self-esteem. Explaining childlessness as a health problem rather than a choice may reduce stigma (Greil and McQuillan, 2010), but it means women with TS have to disclose a health condition which also carries stigma. The double stigma of both infertility and TS means the need to disclose both conditions to a partner may consequently be a barrier to developing a relationship in which to have a family.

Compliance with social norms of motherhood means not simply having children, but having them at the right time. Both infertility and chronic illness have been conceptualised as 'biographical disruptions' (Bury, 1982; Greil, 1991): a diagnosis forces people to reconsider their future life trajectory, re-evaluate their identity and, in response, revise their life plans. Infertility is thus cast as a disruption to the ability to achieve both a desired and a normative life course trajectory, where time is culturally understood as a linear progression through life, and infertility is addressed in adulthood (Becker, 2000). The impact of infertility is gendered: women have been identified as more affected than men (Greil, 1991; Sandelowski, 2016), and more stigmatised, since fertility and motherhood were considered more salient to women's identity. The concept of biographical disruption was developed to theorise the impact and management of chronic illness in adults; Williams (2000) argues that it does not apply as readily to children, who are still developing their sense of self and whose anticipated life trajectory is shaped by their condition from an early age. Similarly, biographical disruptions either of illness or infertility are often experienced in, and influenced by, relationships with others (Hudson et al., 2016). This paper shows how attitudes towards infertility are shaped by a diagnosis of TS in childhood or puberty, meaning reproductive options are anticipated for years, both by girls and women with TS, and by mothers of girls with TS. For these reasons, it is important to consider ways of looking at time and reproductive timing that can accommodate conditions diagnosed in childhood, and their impact beyond the individual.

When considering non-conformity with social timing, a concept of time as a linear progression through life, with definable goals and a socially-defined timetable in which to achieve them, remains a useful backdrop against which the experience of women with TS and mothers of girls with TS can be contrasted. Roth (1963) characterises a life course, and the series of events within it, as a career; each career has an end-point or goal, definable stages of progression, and clear points of 'promotion' where people move from one stage to another. Everyone in a social group is under the same kind of social pressure to progress along the schedule at the same rate as their peers, regardless of how feasible this is for individuals. 'Clues for constructing timetable norms' (Roth,

1963 p95), such as marriage or buying a house, act as markers of progression on the reproductive ‘timetable’, and as points of comparison with peers, which measure the degree of success in achieving expected life goals. While there have been considerable changes in parenting practices since the 1960s, fertility and parenting is still seen as an expected life goal that is primarily a concern of women (Greil, 1991; Faircloth and Gurtin, 2017). Even in non-normative relationship settings, women come under pressure to conform with traditional parenting ideals related to relationship formation and pregnancy timing (Herbrand, 2018). As this will be described later, discovering infertility, particularly in childhood, ruptures the socially expected and imagined future life course as flowing seamlessly towards an established relationship and parenthood.

Garland-Thomson contends that the practice of norming around social timetables is based on a universal ideal of human experience, or the ‘normate’ (Garland-Thomson, 2011, p8); this misrepresents the average or majority experience as normal and aspirational, thus marginalising and stigmatising those who ‘misfit’. Misfitting describes points in time when there is an incongruent relationship between normative reproductive timing and an individual schedule which has been disrupted by chronic illness and infertility, which happens for women with TS; these are points where people need to account for their misfitting in ways which manage and minimise the associated stigma. Roth’s theory is also helpful here to describe how people who repeatedly miss scheduling deadlines are deemed ‘timetable failures’ (Roth, 1963 p106), and are no longer considered part of the peer reference group.

A more flexible and expansive approach to temporal misfitting is the concept of ‘crip time’ developed by Kafer (2013), who reframes ‘queer time’ (Halberstam, 2005) to focus on disability. It de-centres the rigid schedule and deadline expectations of normative social timing, reorienting focus onto the timing norms of disabled people’s lives. Accommodating that people routinely need more time, or timing has to be flexible, requires expanding normative expectations of how long things take and when they should happen. “Crip time bends the clock to meet disabled bodies and minds” (Kafer, 2013, p27), intentionally destigmatising non-normative ways of being ‘on time’. The insider term ‘crip time’ forms part of a critique of the social pressure arising from a societal norm that presumes all people are able-bodied and which overlooks and excludes disability, a concept referred to as “compulsory able-bodiedness”.

Further, the concept of the ‘curative imaginary’ (Kafer, 2013) is used here specifically as an analogy for the social pressure mothers of girls with TS come under to find ways to address their daughter’s infertility. Kafer developed this concept to describe the expectation placed on disabled people to always be looking forward to a cure for their condition, underpinned by a view of disability as a condition where normalising interventions are anticipated and required. Similarly, the social expectation to have children means that infertile women are expected to be anticipating and working towards having a family, rather than accepting life without children. The focus on the future embedded in the curative imaginary has a particular resonance for fertility, which, like disability, is time-sensitive and dependent on context. Thinking around families is often future-focused; people have expectations, for example, about when and how they will have children, when their children will become parents, and about becoming grandparents. Here, the concept is used to explore the way mothers think about and act on these pressures.

3. Materials and methods

The analysis presented in this article draws on a broader study of reproductive choices in the context of TS. This study took a constructivist grounded theory approach (Charmaz, 2014) and was based on a purposive sample of semi-structured photo-elicitation interviews with 19 women with TS and 11 mothers of girls with TS in the UK, conducted in 2017–2018. Ethical approval was received from the Faculty Research Ethics Committee (FREC) at DMU (Application no 1824).

TS affects fertility, so women with TS did not have to be mothers at the time of the interview but needed to have considered whether and how they wanted to have a family. As TS is a diverse condition, the reproductive options available to adult women vary depending on age, access to treatment, and an individual’s medical risk (Cameron-Pimblett et al., 2017). To reflect this, care was taken to recruit women in a range of circumstances.

Mothers of girls with TS were also included to explore views on potential reproductive options for their daughters, including on specific technologies, such as maternal egg freezing (MEF), where a mother freezes her own eggs for her daughter, and ovarian tissue freezing (OTF), where an ovary is removed and frozen, to be transplanted later. MEF is a reproductive choice the mother makes for herself on her daughter’s behalf while her daughter is a child, while prepubertal OTF requires parental approval. Another reason for including mothers was that they tend to have more influence than fathers on their children’s reproductive choices and sexual behaviour (eg Beresford and Sloper, 2008 p82), so they could potentially influence their children’s family building preferences in later life.

Multiple recruitment approaches were employed, including social media; the patient charities; a project website and Facebook page; parenting and fertility websites such as Mumsnet; Twitter; and paid print and online advertising, and word of mouth.

Recruitment followed a constructivist GT approach (Charmaz, 2014). Participants completed a screening survey: women with TS were asked their type of TS if known, relationship and parental status, age of siblings, how they had become a parent (if relevant), and the family building options they had considered. Mothers of girls with TS were asked about their daughter’s circumstances, if they had other children, and what they were doing to plan around their daughter’s fertility issues.

The sample consisted of 30 participants: 19 women with TS, 11 mothers of girls with TS. Women with TS were aged 21–60. Mothers were aged 33–52 and their daughters from 5 to 27. All participants who disclosed their ethnicity were white British or white Other. Twelve participants with TS were married or had a long-term partner, while six were single. Five had children: three through egg donation, one through adoption, and one through natural conception. Of the 14 participants with TS who did not have children, eight had chosen adoption or egg donation but had not yet acted on it. Three had no children for health reasons, two were undecided at the point of interview, and one was childfree.

Photo elicitation interviews (Harper, 2002) were chosen to increase the agency of participants in discussing this sensitive subject (Liamputtong, 2007). Consideration was given to the access needs of women with TS (described in Fearon, 2019) and to wider accessibility issues (Aidley and Fearon, 2021), as well as the potential for the interview to cause distress. Participants were asked about diagnosis, the impact of TS on their fertility, and their views on a range of reproductive options including living without children, and MEF. All participants were interviewed in their home or a nearby public place which they chose. Interviews lasted 90–120 min and were digitally recorded with consent.

Data for the two groups were transcribed then coded separately in NVivo throughout the data collection period. Codes for each were then separately imported into mind mapping software and refined into conceptual categories; finally, three overarching theoretical categories were developed using both sets of data. One of these categories, timing, is discussed in this paper. This article looks next at how social timing is impacted more broadly in women with TS and mothers of girls with TS, moving on to focus on its impact on reproductive timing.

4. ‘Crip time’ and TS

This section looks at how ‘crip time’ applies in the context of TS. It explores how, beginning in childhood, TS disrupts the taken-for-granted timing of life course events in ways that often produce visible lack of

conformity. It is articulated through the ways that timing varies from social timing norms, and how this is anticipated, and pre-empted or managed, by women with TS and mothers of girls with TS. Two dimensions of Kafer's wider framework of 'crip time', 'strange temporalities; and 'imaginative life schedules', are drawn upon to show how participants both resisted and conformed with timing norms. 'Strange temporalities' (Kafer, 2013, p35) refers to the points at which normative timing is interrupted to make it obvious when a girl or woman with TS misfits with her peers, misfitting which then needs to be accounted for. 'Imaginative life schedules' (Kafer, 2013, p38) expresses how disabled people navigate or renegotiate their relation to time based on their current or perceived future needs, choreography which enables them to manage events to suit them better. Together they present a picture of the way families affected by TS manage its impact.

4.1. Strange temporalities

The concept of strange temporalities describes points or periods in which people's social timing differs from that of their peers in ways that make them stand out as different. The concept of misfitting (Garland-Thomson, 2011) is used alongside it to characterise the variation from normative timing as stigmatised rather than neutral. Misfitting with peers was a common experience for both women with TS and mothers of girls with TS; for example, girls and women misfitted at diagnosis, at puberty, and when forming relationships. This section looks at when this happens and the strategies and explanations used to account for and, often, to normalise differences.

Most girls with TS have delayed physical growth, which is usually managed with daily growth hormone injections. Most participants described this as an unwelcome, tangible sign of difference which needed to be explained to their school and other carers, not least because the injections cause bruising, visible during sports activities (Kaptein, 2013).

"As soon as growth hormone stopped, I was grateful. That was the big thing that made me stand out, or that made me think, 'OK, I have a thing'." [TSW15: woman with TS, late 20s]

An early diagnosis of TS, including disclosure of future infertility, also means that girls face issues that require emotional maturity far earlier than their peers. Some women described being told they were infertile before they were old enough to understand the implications, which they only realised over time. Yet girls may be simultaneously more mature than peers in terms of their life experience, but less mature, due to delayed emotional and physical growth (Wolstencroft et al., 2019), both signs of TS. In the strange temporality of TS, there is a disconnect between the normative trajectory of emotional maturity and the physical age at which girls have to address these weighty issues.

"They'd told me the options in terms of IVF via egg donation and things like that, I was just like, oh, OK, when the time comes, that's what I'll do, then, you know. And then just carried on, really. I think it was only as I got older that I sort of realised more, how not necessarily guaranteed it is." [TSW17: woman with TS, early 30s]

The impact of finding out about infertility can be devastating. One woman knew from early childhood that she had TS, but found out when she was 12 that it meant she was infertile. She described her huge sense of loss, and the way her feelings were dismissed by the adults around her, due to her age.

"Because of the way we're brought up, you think you're fertile. It's just something you don't question, you don't wonder if I am or not at 10 or 11, when you first become aware of how things work. [...] My doctor's attitude is, you never were, so you haven't lost anything. You never had any ovaries to lose. But to me, I did. There was children that I was going to have and the grandchildren I was going to have – I lost them." [TSW14: woman with TS, early 40s]

Because puberty is usually delayed or absent, it needs to be initiated with oestrogen tablets (in the form of the pill or HRT); consequently, girls may face assumptions about early sexual activity.

"People couldn't understand why I couldn't [have periods naturally]. Because I explained that I'd had to take tablets [...] It was like, 'oh, are you on the pill?' [disapproving]. You know, 'my mam says you're on the pill'. No, no, no, it's not like that." [TSW13: woman with TS, early 50s]

Moreover, some girls with TS have difficulties in social understanding and low self-confidence; this can impact friendship-formation at any age, but particularly at school, meaning girls can be isolated, appear less emotionally mature than their peers, and have trouble fitting in.

"It is very stressful. [...] You just don't know how to conduct yourself half the time or you read too much into things: oh, I said this, and their reaction was this, so that means they hate me!" [TSW9: woman with TS, late 20s]

Self-esteem issues associated with later emotional development, and infertility, also mean that women with TS may start to form relationships later than their peers (Gould et al., 2013).

"For me, I just didn't feel ready at the same time as my friends did. They were ready for all that. I was just quite quiet, shy and withdrawn and just happy in my box I suppose." [TSW16: woman with TS, mid-20s]

Finding the support and friendship of other women with TS was an important way to establish a different temporal fit. Roth (1963) describes how a person whose life is not aligned with the expected career timetable for their peers may find a better fit by comparing themselves to a different reference group. Most women with TS described the affinity they felt with other women with TS, especially the friendships they made through social networks focused on a specific condition, such as the patient charities.

"I felt so much more comfortable than I ever had with people at school, with anyone else I'd met. You just feel totally different. You feel like, they're totally on your wavelength, definitely." [TSW16: woman with TS, mid-20s]

Another woman with TS observed that improved medical treatment and better medical and emotional support for girls with TS was helping to normalise girls' developmental timing.

"Their issues are getting more and more in line with their peers in what they do and when they do it. [...] There's a lot of the women that are in relationships now in their 20s. It's great!" [TSW12: woman with TS, late 40s]

Girls and women with TS may experience temporal misfitting at many points, but involvement with TS-focused social groups, making friendships based on common experiences and sharing strategies for managing physical and mental health, enables many women to experience fitting, through sharing common experiences with peers.

Mothers' time also became crip time, both in the additional time and altered schedule needed to help their daughter manage the condition, and in the additional work undertaken to normalise temporal misfitting for their daughter and others in charge of her care. They experienced misfitting in a number of ways: in needing to address fertility and puberty issues with their daughter earlier than expected, in the lack of understanding of their experience of parenting as being different from the norm, and in the time-management required for the intensive, regular nature of their daughter's treatment. Garland-Thomson (2011, p4) observes "misfitting demonstrates how encounters between bodies and unsustaining environments also have produced segregation". Some mothers reported that they chose to avoid sharing their child's ongoing health and development issues, to avoid the emotional work of having to

explain the impact of TS to people without experiential knowledge of disability. Others found that family members glossed over the impact of TS on their daughter to minimise the stigma they associated with it. This meant that TS-focused parenting groups were vital spaces for mothers to find support.

Mothers frequently described the intense nature of the scheduling and planning required to achieve this. The open-ended nature of a TS diagnosis also made this challenging, as it was not always clear which of the large number of TS comorbidities may affect their daughter in future, or to what degree, making it hard to estimate the 'workload' involved.

"Our daughter's first 6 weeks of school, I think she had 6 appointments to go to [...] I feel like I have a lot of information in my head about our daughter and her health and the people we have to see and the questions I need to ask and the things we need to know, and pre-empting things might happen." [TSM9: mother, early 30s]

Their schedule was both reactive, based on their daughter's response to treatment and her emotional maturity, and anticipatory, based on when her classmates started to reach puberty, a point at which their daughter and other people might start to ask about the implications of TS.

"There is that element of thinking about it for her, trying to foresee what the stumbling blocks might be and deal with them before they become a problem. I suppose it's a kind of, it's not even wearing, it's just ... [sigh] next!" [TSM1: mother, late 40s]

Mothers described how they 'bent the clock' by managing timing challenges to reduce the impact of TS on their daughter. They did this by anticipating her needs and then prioritising. The demands of the girl's ongoing medical and educational needs absorbed her attention day to day. The number of issues a mother could manage at once, and her assessment of what her daughter could cope with, both affected whether an issue would be addressed or deferred to the future.

The need to have fertility conversations several years earlier than anticipated required mothers to consider ways to convey potentially upsetting information to a child who may be perceived to be less well-equipped to cope. Mothers described the challenge of finding the 'right time' to discuss important matters such as puberty and fertility with their daughter, and the need to find 'age-appropriate' ways to do so, such as by incorporating it into everyday activities like reading.

"Our friends that are looking for an egg donor, I've said to her, that's what our friends are doing. When we've got to that page of the book ['Recipes of how babies are made'], that's how they're trying to have a brother or sister for their little boy." [TSM10: mother, mid-40s]

There was general agreement that this needed to be a planned conversation in order to share age-appropriate information and because of the potential for their daughter to be upset.

"I am not saying that I've got a specific timeline, 'by the time our daughter is 6 I am going to have told her', but I know the next coming years, it's got to be the topic of conversation." [TSM9: mother, early 30s]

Several mothers talked to teachers to make school discussions of fertility more inclusive of infertility and delayed puberty, to avoid their daughter misfitting with peers. Mothers actively worked to reframe her experience to create normalising narratives which supported their daughter in feeling that she belonged in her peer group.

"I want them to word something which goes something along the lines of 'not everyone will have babies naturally and that's okay, and there are lots of different families and different options, and IVF is possible'." [TSM11: mother, mid-30s]

Fertility consultations could be particularly challenging. One mother accompanied her teenage daughter to a fertility clinic for an egg freezing

assessment and felt conscious that they stood out in the waiting room.

"I'm there with my 14-year-old daughter waiting to speak to someone about fertility treatment. You shouldn't even be thinking about having babies!" [TSM7: mother, mid-40s]

For mothers, 'strange temporality' meant that as their daughter's social and physical development misfit with the socially expected schedule, in turn they misfit with peers who had unaffected children. Mothers managed time on their daughter's behalf, describing the work required to accommodate misfitting as a series of sometimes very challenging management tasks. To avoid becoming overwhelmed by doing too much at once, or overwhelming their daughter, some mothers prioritised and scheduled the issues that needed to be addressed, deferring some to the future if they could.

4.2. Imaginative life schedules

The concept of 'imaginative life schedules' relates to the ways in which disabled people navigate or renegotiate their relation to time based on their current or perceived future needs. There are three ways in which TS delays or disrupts adult women's anticipated life pattern of marriage and children: relationship formation; disclosure of infertility; and finding alternative pathways to parenthood. Women with TS must construct an alternative way of understanding life progression through adulthood and explain this to others. Indeed, as their wider peer group begins to have families, women may feel they are being left behind.

Like many women considering parenthood, most women with TS preferred to have a partner first. For some women, social cognition issues and anxiety associated with TS could act as a barrier to relationship formation, making dating very stressful.

"It [online dating] made me go, you know, no. This is making me so anxious and sick with anxiety that I just – I'm just going to cut this off. I'm just going to not message them and get on with life for a while." [TSW16: woman with TS, mid-20s]

The need to disclose infertility could also present a barrier, as women perceived this as a point where the relationship might end. Some participants had never had a relationship where fertility and family-building became part of the conversation. Five women with TS said they pre-empted the possibility of rejection by repeatedly avoiding intimate relationships.

"It made me keep men at arm's length because I knew that if they were going to be with me it would have to be without children, and how could I ask them to do that?" [TSW12: woman with TS, late 40s]

Many women with TS developed disclosure strategies which helped them decide when to tell and enabled them to feel in control of the anticipated stigma.

"I never sort of openly come out and say it [...] Somebody might even ask, do you have children, and at that point you can either just say no, and leave it at that, or you can say no, because I have ... and you can decide then if you're going to say something." [TSW12: woman with TS, late 40s]

"When the relationship started to become a sexual one, talk of contraception comes in, and I felt that was the time to disclose." [TSW2: woman with TS, late 20s]

According to Roth (1963), the schedule of the life course is perceived as a natural progression. However, this definition is itself socially constructed and therefore open to negotiation and reinterpretation. Women also reviewed their normative expectations of the timing of motherhood, shifting their 'time perspective' in response to the barriers and facilitators in their life. Interestingly, as meeting a partner did not have a time limit, but the option to have a child did, some participants decided to focus on becoming a parent without a partner.

"I'm not averse to the idea of a relationship at all, but for me, if I had to choose between a child and a relationship, the child would come first." [TSW17: woman with TS, early 30s,]

Four of the five single women with TS who took part prioritised becoming a parent over forming a relationship. Two more had explored adoption while they were single; one was unsuitable for health reasons, and one had decided against.

"I could wait to meet the right guy and that might never happen, whereas I can adopt and know that I have control over that – I can do it. So, I don't mind doing it on my own." [TSW9: woman with TS, late 20s]

By consciously rescheduling the timing of parenthood to suit their circumstances, they challenged dominant societal expectations about the need to be in a stable relationship before having a family.

Another way in which women with TS adapted to the possibility of not becoming a parent was through non-parental relationships with children, such as being an aunt, step-parent or godparent. These roles can be significant, given that, currently, less than a third of women with TS become a parent (Gould et al., 2013). While some women with TS struggled with the emotions brought up by spending time with children, others enjoyed it. 'Involved aunthood' (May and Lahad, 2019) gave women a defined, non-parental role in the life of a child in their family, which enabled them to spend time with children.

"I used to spend a lot of time with the girls when they were kids and that, running round, sleeping over, then my mum coming in and next morning and we were like this [mimes being flaked out] on the sofa because they'd kept us up half the night talking and messing around, and then up and wanting breakfast. Oh, it was all good fun, I got the most out of them, definitely." [TSW13: woman with TS, early 50s]

Kafer (2013, p40) suggests that 'crip time' challenges 'the normative modalities that define time, such as productivity, accomplishment, and efficiency, as they urge us to something different'. These relationships place women with TS in the same generational alignment with their nieces, nephews and stepchildren as the child's parents. Through them, some participants found a way to experience caring for a child in their family at the time of life when normatively they would be expected to be parents, without facing the uncertainty, risks and costs of fertility treatment or adoption. This could provide a positive way to fulfil the desire to be a parent in women who wanted to have a family, and a bounded relationship with children for women who did not.

5. The curative imaginary and reproductive futures

After exploring the timing issues of TS using the framing of 'crip time', this section examines how mothers of girls with TS navigate the knowledge that, in future, their daughter will not have children naturally, within a broader cultural narrative of reproductive chrononormativity (Freeman, 2010). It takes the concept of the curative imaginary (Kafer, 2013), that the only socially acceptable attitude for disabled people to have towards their disability is to search for a future cure, as an analogy for infertility, where infertile women are expected to look for ways to have a family, and where having a family is seen as a 'cure' for infertility. It is used to show the social pressure that mothers come under to anticipate and provide solutions for their daughter's future infertility, on her behalf, when she is diagnosed in childhood.

The mothers in this study felt it was part of their role to find potential solutions to their daughter's infertility, including considering uncommon options such as MEF. This form of intrafamilial donation is widely known within the TS community, but rarely practised. The decision-making process and relational complexities of MEF are not addressed here (see, for example, ESHRE Task Force, 2011), but frozen maternal eggs can give the security of knowing that eggs are available for the future, while reassuring the mother that she has acted to help her

daughter achieve motherhood in later life. Most participants commented that, regardless of whether they personally thought MEF was acceptable, it was the type of behaviour that fitted with norms of maternal love and duty.

"As a mum you do everything for your kids to keep them happy." [TSM7: mother, late 40s]

"I can see why they would do it, I get why they would do it, but no." [TSM3: mother, mid-40s]

Some mothers framed fertility and motherhood as an expectation that their daughter would have in adult life, particularly at times when they observed their daughter's maternal behaviour when playing with dolls or interacting with other children. This often triggered grief and raised questions about what she would want in the future.

"The way she is trying to jig him [baby brother] or rock him to stop him from crying are exactly the things I do. So I guess I see her as a mini-mother, and that's why I think to myself, I would assume that she would want children. But obviously as she is older, I won't make that assumption, it is her choice." [TSM9: mother, early 30s]

All the mothers in this study were aware of MEF; one had frozen her eggs, three said they would have done so if it was possible; four were ambivalent, and the remaining three would not choose MEF themselves. The following mother had frozen her eggs, reasoning that she would feel personally responsible if she had not offered her daughter a source of genetically related eggs:

"I was kind of aware that my role for her in her infertility wasn't a 'grandparent' role, it was a 'being a mum' role, in helping her, and I wanted to do whatever I could to make that as easy as possible for her." [TSM1: mother, late 40s]

This sense of responsibility was focused on their daughter's anticipated future desire for motherhood. The expectation that infertility is an undesirable condition which must be alleviated (for example, through adoption) or treated (through the use of ARTs) mirrors the expectation expressed by the concept of compulsory able-bodiedness, that disabled people should be working towards a future cure. This normative expectation was expressed both by the mothers who took part, and people in their immediate social circle.

"Someone once said to me, 'wasn't it a shame that you didn't have two girls.' [...] And other friends have said to me, oh, do you think maybe her cousins ..." [TSM6: mother, mid-30s]

The use of MEF could be further complicated by its timing: egg donation normally takes place before the age of 36, and at this point, the daughter is likely to still be a child and not old enough to have an informed view. Deciding on and paying for MEF could be constrained by competing demands on the family, such as the finances involved in having young children, or familial caring responsibilities.

"You can't, in five years' time, go, oh, I'm ready for that. And at the time, I probably was 31 at the time of diagnosis, I would say it has taken me a good three years [to be able to think about it]." [TSM6: mother, mid-30s]

These factors made it hard for mothers to anticipate what their daughter might want. Anticipated decision regret (Tymstra, 2007) describes how decision making is informed by the prospect of regretting the outcome in the future. However, MEF was not a clear-cut choice. Some mothers worried that, whatever they decided to do, there was a risk that it would turn out to be the wrong choice.

"I have mixed feelings because if I she ever comes to me and says, why didn't you do that, it's too late. You then haven't given her that option." [TSM6: mother, mid-30s]

Tymstra (2007) observes that people can find it difficult to decline to

use medical technology, partly due to concerns that they might regret not using it, so the availability of MEF can present a dilemma. Half of the mothers who participated were conflicted about rejecting MEF, even though they had misgivings about its use:

“In my own circumstances I was glad that it couldn’t happen. If it had been possible and it was something that our daughter wanted, I would have done it, probably against my better judgement, and maybe lived to regret it.” [TSM7: mother, mid-40s]

The social pressure imposed by a social imaginary of cure also became evident when looking at mothers’ approaches to intrafamilial egg donation and to the potential future risks of pregnancy. Some looked to social and familial networks as a potential source of genetically-linked donated eggs: three had considered conceiving another daughter who may later become a sibling egg donor. One mother with two daughters in their early teens described how she had tentatively raised awareness of sibling donation with them.

“I just sort of casually talked about just so it’s almost sort of in their heads for when they are older.” [TSM3: mother, mid-40s]

Moreover, taking steps towards the anticipated future ‘cure’ may conflict with social imaginaries of motherhood that focus on safety and care, such as when the anticipated pregnancy may be high risk.

“You’re kind of on this roller coaster [...] When I realised she would be able to have children, that she could carry a baby [...] – oh brilliant, brilliant! And then you find out that, actually, they have a much higher risk of all these other complications during pregnancy and your hopes are slashed again.” [TSM10: mother, mid-40s]

In addition to the sense of responsibility for facilitating a high-risk pregnancy, the other choices and challenges this might bring in the future could be overwhelming.

“What if she doesn’t want to use your eggs? What happens to those eggs then? Do I give them to other people? I don’t know.” [TSM6: mother, mid-30s]

Although all the mothers who took part had considered their daughter’s options, there were limits to what they could do, so they looked for alternatives. Several families could not afford fertility treatment, instead talking to their daughter about a range of future ways to have a family. Conscious of the high cost of fertility treatment, some had started saving while she was a child.

“We’d already said [...] we will put money aside and we will save and if our daughter wants IVF, that’s what she’ll have.” [TSM5: mother, mid-30s]

When imagining the future, mothers envisaged varied pathways for their daughter, beyond the use of reproductive technology. Several said that their daughter may be child free. One worried that her daughter may not be approved to become a solo adoptive parent; another suggested that she might be a lesbian with a fertile partner. Due to the potential risks of pregnancy, others said they would be relieved if their daughter decided not to pursue assisted conception. But mothers could not predict how their daughter would respond to being infertile, so they did not know which steps to take to best protect her from future heartache.

A future focus was also evident in the way that participants anticipated developments in fertility technology that could eventually obviate the need for an egg donor and offer the possibility of a genetically connected child, such as artificial eggs and ovarian tissue freezing. These experimental treatments are examples of the way in which ARTs can act both as hope technologies (Herbrand and Dimond, 2018), and as tools of ‘anticipatory regimes’ (Balliff, 2022) which facilitate and reinforce the social norm of family as being genetically linked.

It is interesting to observe that originally, the concept of the curative imaginary was used to argue that imposing a narrow range of ‘curative’

future options is ableist, and that non-normative choices that suit disabled people should be encouraged and respected. Mothers of girls with TS were both aware of and accepting of the prospect of their daughter making non-normative parenting choices herself, as an adult. However, when making decisions on her behalf, mothers who took part did not feel that it was acceptable to take no remedial action and instead, help their daughter to come to terms with infertility: as Robertson (2015, p5) puts it, there was no sense that infertility could be ‘simply accepted as a possible way to be’.

Kafer (2013, p46) suggests that the stigma of disability means that disabled people risk being written out of the future, ‘rendered as the sign of the future no one wants’. Similarly, futurity can be used in the service of mandated maternity, with infertility, and its anticipated social consequences, presented as the future no one wants. Where a failure to plan for the future is judged as a failure of mothering, and where the use of ARTs is considered a potential, or even preferred, ‘cure’ for infertility, mothers may feel pressure to consider MEF even if they are not completely comfortable with it. Frozen maternal eggs could provide insurance for the future but could also defer the dilemma of whether to use them into the future, shifting the decision from the mother onto the daughter.

6. Conclusion

This article has demonstrated how a childhood diagnosis of infertility can affect thinking around reproductive timing in the context of TS, showing how women with TS and their mothers anticipate, circumvent and resist the double stigma of infertility and chronic illness. Using two dimensions of ‘crip time’, strange temporalities and imaginative life schedules, it has described how both women with TS and mothers of girls with TS manage the various ways they misfit with normative expectations of social timing.

Women with TS misfit, both in childhood and as adults, in part due to delayed physical and emotional development and the need to take growth hormone and oestrogen. Receiving an infertility diagnosis as a child could be devastating and was not always managed sympathetically by adults, or fully understood by peers. It could later be a barrier to forming relationships. Mothers of girls with TS described how they felt excluded from their peer group of parents, as the life course of their children was so different. TS support groups provided an important peer comparator for women with TS, and mothers, where they could feel a sense of fitting in, and where issues around timing were normalised.

‘Crip time’ also usefully frames how people anticipate situations where they will experience stigma and how they approach it or push back against stigmatisation. The ideal of most women with TS who took part was to have children with a partner, but in addition to infertility they faced social barriers, including anxiety around the stigma of infertility disclosure and their need for a comparatively early timing of pregnancy. Some managed by keeping their distance from partners, or taking their time, while others actively took control in a number of ways. Having a strategy for the best time to disclose infertility enabled women with TS to feel more in control, and potentially less vulnerable to rejection. Four women with TS rejected the expectation to passively wait to meet a partner and actively explored solo parenting. Others enjoyed having children in their lives through the children of family, friends or a partner. Infertility was considered a significant issue by both groups, and mothers felt responsible for addressing it in ways which offered their daughter hope and choices. This included facilitating the option for their daughter to have genetically related children by enabling or encouraging sibling donation.

This article has shown that the timing of diagnosis means planning for decisions around reproduction in the context of TS is often anticipatory, informed by social imaginaries of infertility as undesirable, and by maternity as a likely future wish. Kafer’s (2013) concept of the curative imaginary has been applied to the case of infertility, showing that, as disabled people are expected to be working towards a cure,

infertile women are expected to work towards becoming a mother. This concept allies with future-focused concepts based on imaginaries of motherhood, such as the motherhood mandate and anticipated decision regret, extending them from adults making decisions on their own behalf, to mothers making choices which affect their child. In doing so, it has showed the usefulness of ‘crip time’ and the ‘curative imaginary’ in illuminating choices made in the context of a lifelong chronic illness impacting timing from childhood, and reproductive timing in particular.

Mothers’ activities around planning for their daughter’s future family-building, including MEF, could also be seen as ‘anticipatory labor’ (Wu, 2023 p13) as they consider how best to navigate pressure to achieve desirable future outcomes for their child. Mothers of girls with TS and women with TS are making relationship and reproductive choices within anticipatory regimes which prioritise achieving pregnancy above other options. The timing of these choices is one important complicating factor which merits further investigation, and the perceived risk to relationships is another, both to the anticipated relationship between the mother and daughter and also to the anticipated relationship between the woman with TS and a future partner. Finally, the concept of mandated motherhood (Russo, 1976) can be extended to mothers of girls with TS: social pressure and anticipated future distress, blame and infertility stigma could pressure mothers into feeling they must provide for their daughter’s reproductive future.

The findings of this research add to a very small body of literature on the lived experience of TS and the way women with TS make reproductive choices in adulthood. It shows how these choices are anticipated, and the stigma associated with infertility is managed, re-framed and resisted by women with TS and mothers of girls with TS. Findings may be applicable more widely to other contexts where families discover a child is likely to be infertile in adulthood and subsequently feel pressure to anticipate possible outcomes and solutions. This research therefore may be useful both for practitioners supporting families, and families themselves. The concepts of ‘crip time’ and the ‘curative imaginary’ could also apply more generally to reproductive choices in chronic conditions beyond TS. This article demonstrates the cross-disciplinary potential of applying disability studies concepts to the context of infertility and chronic illness. These concepts shed new light on the dimensions of timing and anticipation in this context, improving our understanding of the lived experience of women with TS, and how they view and use reproductive technologies.

Data availability

The authors do not have permission to share data.

Acknowledgments

Many thanks to the participants, and the patient organisations, the Turner Syndrome Support Society and Ragdolls UK, for their support of this project. This work was supported by a Mildred Blaxter Post-Doctoral Fellowship from the Foundation for the Sociology of Health and Illness.

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