Chapter 10

Navigating normativity: Understanding reproductive loss in the lives of young adults with shortened lives

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Abstract

Until quite recently, many of those with life-limiting or life-shortening conditions died in infancy or childhood, with very few reaching adolescence or adulthood. Advances in medicine and clinical care have changed this picture and many of those diagnosed with these conditions are reaching adulthood and beyond. Transition into adult life opens new opportunities including the potential for sexual exploration, intimate relationships and having children of one's own. However, for those living with life-shortening conditions these opportunities are often curtailed and difficult to achieve because others assume that they will not reproduce. This chapter explores the concept of reproductive loss within the lives of young adults with shortened lives. In particular, it considers the normative assumptions of embodied limitations, assumed infantilisation and the imperative of moral responsibility, which serve to frame young people's reproductive beliefs, aspirations and choices.

Introduction

Children and young people with life-limiting or life-threatening conditions were not typically expected to grow up and grow old. Indeed, many infants and children with such diagnoses do not reach adulthood. So, although most young adults living with such conditions still have shorter lives, increased life-expectancy has enabled new aspects of social and family life to open. This includes thinking about all aspects of reproductive life including contraception and fertility, and childbearing and parenthood. Reflecting on the concept of 'reproductive loss', this chapter considers these issues in the context of a dominant pronatalist ideology that frames having children as an important *rîte de passage* and part of a ‘normal’ transition to adult life, even in the context of (often severe) disability, (frequent) ill-health and living with a condition which is likely to shorten life.

The chapter reflects on the range of reproductive losses that often frame the lives of young adults living with conditions that are likely to shorten their lives and the way that young adults navigate the normative expectations that they will not (typically) reproduce. The chapter begins by exploring how a broad understanding of what it means to experience reproductive loss can serve as a conceptual framework for understanding reproductive futures that are uncertain, difficult, or denied. The chapter then moves on to consider how reproductive loss may be experienced by this group of young people in the context of three normative social, and/or biomedical assumptions. First, that of embodied limitations – the assumption that young adults with shortened lives (probably) cannot have sex, become pregnant, bear a child or parent one. Second, that of assumed infantilisation – the assumption that, whilst chronologically and legally having reached adulthood, they are effectively still children in the eyes of others. Third, the imperative of moral responsibility – the assumption that provides a regulatory failsafe should assumptions one and two not hold true; that young people with shortened lives would be expected not to reproduce for the greater good. Given that there is limited evidence and research on the reproductive experiences and expectations of young adults with life-shortening conditions, at the end of this chapter I address the major gaps in current knowledge and consider directions for future investigation, policy, and practice.

Reproductive loss: A conceptual framework

‘Reproductive loss’ is typically used in the literature – and in a range of multi-disciplinary academic and professional contexts – to refer to a heterogeneity of reproductive traumas including miscarriage, ectopic pregnancy, molar pregnancy, stillbirth, spontaneous and induced abortions, perinatal and neonatal deaths (for example, see Cecil, 1996; Layne, 2003; Martel, 2014; van der Sjipt, 2018a; Austin and McGuinness, 2019; O’Donnell, 2019, van der Sjipt, 2022). Some scholars have widened this definition to also include reproductive experiences such as the challenge of coping with infertility (for example, see Price, 2008). Inhorn (2007), adopting an anthropological perspective, uses the alternative phrase ‘reproductive disruptions’ to refer to a wide range of ‘distressing experiences’, which include infertility, adoption, and the birth of a disabled child.

Although commonly used, the terms reproductive ‘loss’ and reproductive ‘disruption’ have been criticised for their negative associations with ‘disturbance, abnormality and eventfulness’ (van der Sjipt, 2022, p. 354); this is problematic since not all ‘losses’ or ‘disruptions’ are experienced as such and may in fact provide positive opportunities for change or growth, or in the longer term, could be experienced more neutrally. In recognition of these critiques, van der Sjipt (2018b) prefers to use the term ‘reproductive interruption’ instead, acknowledging that the extent to which reproductive experiences are felt as a loss or disruption are highly contingent on a range of personal, cultural, social, and political circumstances.

These terms carry the weight of their own politics (Martel, 2014) so while acknowledging this, in this chapter I build on my previous work on reproductive loss (Earle *et al.*, 2008; Earle, Komaromy and Layne, 2012; Earle and Lloyd, 2012) where I used this term to highlight how reproductive stories often focus on the personal, cultural, social, and political normativity of reproductive ‘successes’ rather than on reproductive struggles. As argued elsewhere, and in contrast to the more traditional definitions of reproductive loss outlined above, I use this term to include:

> ‘experiences of early and late miscarriage, termination of pregnancy, stillbirth, perinatal and infant death, as well as maternal death – but also to other kinds of losses relating to reproduction including the loss of “normal” reproductive experience such as that associated with infertility, assisted reproduction and the medicalisation of pregnancies, labours and deliveries defined as “high risk”…. This term address[es] all experiences of non-normative reproduction to include the curtailment of reproductive futures and desires, whether by individual action or social structures.’ (Earle, Komaromy and Layne, 2012, pp. 1-2)

In other words, this broader and more-encompassing definition of reproductive loss takes into account both real and imagined futures and possibilities as well as reproductive futures that are uncertain, difficult, or denied. For example, in previous research I explored the experiences of pregnant women with Type I or Type II diabetes, a chronic long-term condition that is known to have a significant impact on neonatal and maternal morbidity and mortality (Earle and Lloyd, 2012). This study showed how women experienced a sense of reproductive loss when their experiences of pregnancy, childbirth and early motherhood were marred by the intense medical surveillance and monitoring of their pregnancies which was at odds with normative, idealised, and desired notions of ‘normal’ carefree pregnancy. Women reported how the labelling of their pregnancies as ‘high risk’, persistent judgement on their behaviours, lifestyle choices, and a focus on their medical condition (rather than on the pregnancy itself) were infantilising and had significant consequences for their ongoing reproductive stories. This backdrop of anticipated normalcy and idealised social expectations (Earle and Letherby, 2003) is particularly important to the conceptualising of reproductive loss as a framework that can be used to understand a wide range of reproductive struggles, including those of young adults with shortened lives. For example, writing about reproductive loss in the more traditional sense, Layne (2003) considers how cultural narratives of 'pregnancy failure' are a social message of personal (rather than biological and/or biomedical) failure whereby the individual is not able to fit into idealised social expectations of motherhood and parenting. In this context reproductive loss in understood as a failing to live up to standard social norms regardless of the individual's position in relation to that loss.

It is widely acknowledged that reproductive loss, in both its narrow and wider interpretations, is an ubiquitous phenomenon globally. Of course, reproductive loss can be understood in different ways across time and space and so it is imbued accordingly with multiple meanings. Understanding of it is complicated further by the blurred boundaries between that which is intentional or unintentional, induced, or spontaneous; experiences of reproductive loss are thus personally, socially and culturally ambiguous (van der Sjipt, 2022). As O'Donnell (2019) argues, reflecting both her pro-choice Christian perspective, and her personal experiences of multiple miscarriages, not all women who experience reproductive loss will feel upset or will feel the need to mourn so while acknowledging that it is common 'the reactions and responses to it, and the meanings assigned to it' (p. 147) are often very individual ones. For many, reproductive losses are typically highly significant events that can profoundly affect people's lives, those of their families, and wider communities. The literature refers to wide ranging consequences including a fear of future pregnancy and childbirth (Earle and Lloyd, 2012), an impact on self-identity (Murphy, 2019) marital and relationship collapse (Gold, Sen and Hayward, 2010), the risk of complicated grief[1] (Kersting *et al*., 2011), impact on future children

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[1] A more complex, disruptive and pervasive grief that is thought to differ from a more 'typical' grief reaction.

and parenting experiences (Üstündağ-Budak *et al*., 2015) and a loss of social standing within the community (for example, see van der Sjipt 2018a; 2022).

Consistent across the scholarly literature on reproductive loss is acknowledgement of a pervasive silence that often surrounds experiences of loss; a silence that has been described as 'deafening' (O'Donnell, 2019). Kristvik (2022), who explores reproductive loss through stillbirth, argues that while 'The loss of a significant other is a universal but demanding and transformative life event' (p. 504) there is a very precarious space for mourning after stillbirth. Reproductive loss, in the traditional sense, is thought to be a form of disenfranchised grief (Doka, 1989) in that it is often experienced privately with few social or public rituals to mark it. In some cultures, reproductive loss is taboo and not recognised. In other words, there can be a 'social obliteration of reproduction loss' where even those who are close to you can misrecognise this loss by not recognising that the loss is significant or real or should be recognised for what it means to the person or persons who have experienced it (van der Sjipt, 2018a).

Taking a psychotherapeutic perspective, and writing about recovery from reproductive loss, Diamond and Diamond (2017) argue that all individuals have thoughts, feelings, and fantasies about parenthood, either conscious or unconscious and that these form part of what they call a 'reproductive story', or narrative. With some specific exceptions (and particularly in relation to the subject of oncofertility) very little focus has been given to the reproductive stories of young adults with shortened lives. As I will go on to argue below, pejorative assumptions are made about the lives and aspirations of such young people and these assumptions serve to ensure that reproduction is institutionally, socially, and individually silenced for young adults living with complex life-limiting or life-threatening conditions. As Martel (2014) has argued when reproductive loss is silenced it ‘becomes the most secret aspect of existence’ (p. 335).

Experiences of reproductive loss: Cannot, do not, or should not have children

For young adults with shortened lives, their reproductive stories are framed by three normative social, and/or biomedical assumptions that serve to silence and limit their hopes, futures, and expectations for a ‘normal’ life; (1) notions of embodied limitation (2) assumed infantilisation and, (3) an imperative of moral responsibility. Fundamentally, these assumptions are based on a belief that disabled young people living with complex conditions that are likely to shorten their lives ‘cannot, ‘do not’ and/or ‘should not’ have children. With some exceptions there is limited research on the subject to date. In part this omission exists because children and young people with life-shortening conditions typically did not and were not expected to live to adulthood but also because of the silence and taboo that exists concerning the sexual, intimate, and reproductive capacities, rights and experiences of this group. Drawing on existing research where it exists, and on other cognate literature from within broader disability studies and learning disability research, I now explore young people’s experiences of reproductive struggle and loss.

Embodied limitations

I use the concept of embodied limitations to describe the assumption that young adults with shortened lives cannot have sex, become pregnant, bear a child or parent one. In this context it refers explicitly to the belief that disabled bodies are broken and malfunctioning and the assumption that disabled people **cannot** (physically) have children. The social theorist Shilling asks: ‘What counts as a legitimate body?’ (1993, p. 145), a question that has been widely discussed in disability studies since impaired bodies are often viewed as ‘abnormal, deviant, inferior and even sub-human' (Loja *et al.*, 2013, p. 191). In short, there is a corporeal standard which young disabled bodies, and people, do not meet. However, all bodies are vulnerable and have their limitations and, as discussed earlier, experiences of reproductive loss are varied and ubiquitous. Letherby (2012), who writes about infertility, argues that:

> 'Motherhood and fatherhood are often taken for granted … an inevitable identity within an individual's lifecourse. So, when social circumstances and physical conditions prevent this the result is often distress'. (p.10)

Although there is limited empirical research on the experiences of fertility and reproduction for young adults with life-shortening conditions, the evidence that does exist points to experiences of reproductive loss and distress.

In my previous research[2] with young adults with life-shortening conditions (Earle and Blackburn, 2021), participants expressed disappointment when others did not recognise their reproductive needs. One young woman said:

> *'I get the feeling that some people – family and professionals – don't feel I need to know about genetic information partly due to their perception that I am not sexually active so no need and also because I have a short life span and won't need info as I won't have children – go figure!'.* (Participant 16 quoted in Earle and Blackburn, 2021)

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[2] An action research project drawing on an interpretivist qualitative framework. Including 16 young adults aged 21-33years, recruited via hospices, who participated in focus group discussions.

Research on the experiences of people with cystic fibrosis shows similar results; although many participants were sexually active, they had had few opportunities to discuss fertility issues with health professionals (Fair, Griffiths and Osman, 2000). Blackburn's doctoral study (2019) involving interviews with young people, family members and professionals offers an additional perspective on this. In her interviews with medical professionals, they often spoke about their lack of training and preparedness in addressing the reproductive needs of young adults with life-shortening conditions reflecting that many doctors '*would not feel skilled, experienced or empowered'* (p. 229). In the same study, parents of young adults with life-shortening conditions expressed similar concerns saying they would have appreciated more information before their child reached puberty. For example, one mother said:

> '… *we would really have appreciated more about how to manage masturbation, wet dreams, erections and none of that was covered and is important for us as parents too, especially now*.' (Precious quoted in Blackburn, 2019, p. 224)

In an interview with Chloe (who has a rare, complex life-limiting condition) and her partner Jordan[3], they speak about their experiences of multiple reproductive loss and how grateful they were to find a medical team willing to support them. They describe themselves as 'very blessed' but acknowledge that they were initially 'judged' and that some professionals did not have enough experience to know how to help them. Chloe describes how she was blamed by others when their first baby died – people assumed that her pregnancy had not gone to term because of her condition, reflecting the assumption that disabled bodies are broken:

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[3] Chloe and Jordan were interviewed as key informants as part of the work of the Open University Sexuality Alliance, a multi-disciplinary, multi-professional and multi-sectoral group working together to champion the sexual and reproductive rights of young people and adults with life-limiting and/or life-threatening conditions. Chloe and Jordan are their real names. The full video interview can be seen here: https://youtu.be/iQ6zOAg41j8.

> *'We had some people saying, we should have expected that but, no, the baby's post-mortem was perfect. We don't know why, it wasn't me. That does seem to be people's first thought and that can be really difficult …'* (Chloe, 2019, online)

While Chloe and Jordan were deeply distressed by their multiple experiences of loss, Jordan paradoxically also describes the joy they felt when they miscarried their first baby. As highlighted earlier in this chapter, experiences of reproductive loss can be ambiguous; although the pregnancy ended in loss, it proved to them and the wider world that Chloe could become pregnant and that her body worked:

> *'…it was one of the hardest moments to find out that our little girl wasn't going to be coming into the world as we'd hoped… we'd had so many aspirations and dreams for her. But, at the same time, it was a door opening, that we knew the first time round when Chloe miscarried, it was a "Wow!" "Fantastic!" "This can happen!" For such a long time we didn't think it could, so it was a magical bonus.'* (Jordan, 2019, online)

As discussed in the introduction to this book, we refer to young adults with life-shortening conditions as a shorthand which recognises that the needs and experiences of this group are not homogenous and sometimes masks important, material distinctions. Distinguishing between young people who are 'life-limited' and those who are 'life-threatened' is important when considering issues of reproductive loss in so far as there is a considerable and growing body of literature about oncofertility whereas there is relative silence on the reproductive experiences and needs of young adults with life-*limiting* conditions. The RCN, for example, urges nurses to address fertility preservation in patients who receive treatment such as radiotherapy and chemotherapy, arguing that young adults and even children should be involved in such discussions as long as conversations are age-appropriate (Kleebauer, 2017). In contrast, in a report produced for Marie Curie's Young People in Transition Programme on children and young people with life-limiting conditions (Marsh *et al*., 2011), only one reference is made to reproduction and fertility. In this instance, the report reflects the concerns of a social worker on the lack of attention paid to these issues:

> *'When a 15-year-old boy was first diagnosed with cancer and prescribed a programme of chemo, no health care professional discussed with him the potential implications for his fertility. Staff often reported that they felt uncomfortable discussing issues of sexuality/fertility with young people.'* (Marsh *et al*., 2011, p. 47).

Note here that the emphasis is, again, on oncofertility, and on the needs of cancer patients within a report that purports to focus widely on the needs of all such young people. In the case of conditions that are life-*threatening*, and specifically in relation to cancer, it is often anticipated that people will survive this and go on to have a long life (Gardino and Emanuel, 2010).

Living with a condition that is likely to shorten your life, combined with the treatment regimen needed to manage it, is most likely going to impact on sex, fertility, and reproduction but this is not a given and depends on many factors. Advances in medical treatment and reproductive technologies means that our understanding of what is possible is malleable and will change over time. Experiences of reproductive loss are very common although not always discussed freely or acknowledged. We are all embodied and all bodies have their limitations, but disabled bodies are often assumed to be broken, contributing to experiences of reproductive loss for young adults with life-shortening conditions.

Infantilisation

Infantilisation implies the prolonging of an infantile state. It refers to how an individual, who is chronologically and/or legally an adult, is over-protected, and spoken to or treated like a child. It usually means that the person subject to infantilisation is not being treated in an age-appropriate way and that their subsequent rights as an adult – such as the right to speak for themselves, act as they wish, and make their own decisions – are not respected. The disability rights movement has long since rejected the notion that disabled people are 'eternal children' (Michals and McTiernan, 2018). Stevenson, Harp and Gernsbacher (2011) point out how:

> Adults with disabilities in general, and those with developmental disabilities in particular, have long been treated as childlike entities, deserving fewer rights and incurring greater condescension that adults without disabilities. (2011, online)

In this chapter I refer to the process and experience of infantilisation to explore how young adults with life-shortening conditions are treated as though they are children. Infantilisation also implies that such individuals do not transition to a phase in adult life where they might be expected to or want to have their own children. In other words, it is assumed that 'eternal children' **do not** reproduce.

While it is widely recognised that disabled people, in general, are often infantilised, young adults with life-shortening conditions are especially vulnerable to experiences of infantilisation. There are three main reasons for this. First, there are many young adults with life-shortening conditions who have associated learning difficulties or disabilities. Some of the medications needed to control the symptoms of life-limiting or life-threatening conditions can impact on a person's cognitive function, and cognitive decline is a feature of some progressive and degenerative life-shortening conditions. There is a long history of the infantilisation of people with learning disabilities or cognitive impairment and this has often meant the curtailment of their sexual and reproductive rights (Tilley *et al*., 2012). Historically this may have involved state-sanctioned sterilisation without consent or through coercion (for example, see Park and Radford, 1998; and, Stefansdóttir and Hreinsdóttir, 2011). More recently this may refer to the control of menstruation and the risk of pregnancy through long-acting contraceptives, which serve as a form of modern chemical sterilisation (McCarthy, 2010; Earle *et al*., 2015). Young adults with life-shortening conditions are often not thought capable of exercising their reproductive agency including the right to make decisions about fertility and contraception.

Second, children and young people with life-shortening conditions did not typically live into adulthood; it was expected that they would die in childhood or adolescence. So, through early death, they figuratively and materially remained eternal children. This is of course problematic for those who are now living with a life-shortening condition but who have transitioned into adulthood beyond original expectations. As Blackburn's research shows (2019; also see this volume), young disabled people are often denied even basic anatomical knowledge of reproduction, and this is strongly associated with the process of infantilisation. However, as one of the parents in her study said: '*We were told that our son would die before he was 16* *years old'* (Precious quoted in Blackburn, 2019, p. 153). Children were not expected to become adults and so issues concerning sex, intimacy, fertility, and reproduction were neither relevant nor important.

It is often common that when someone is chronically ill or disabled, that other people only 'see' the condition or disability rather than the person. This is when the condition becomes that person's 'master status' (Hughes, 1945). On other words, the condition or disability becomes the primary identifying feature of that individual, and determines how others treat you, or behave around you. In a study of study of young people with thalassaemia or sickle cell disorder (Atkin and Ahmed, 2001), most respondents described their experiences of infantilisation. Participants said that parents over-protected them and that medical staff patronised them, not appreciating that they were experts in their own condition and should be consulted about their care.

The risk of death is ever-present in the lives of young adults with life-shortening conditions in that uncertainty and risk are constant companions, even though that risk is not always at the fore. Writing specifically about the role of palliative care in end-of-life and the importance of sexuality, Higgins and Hynes (2009) argue that although palliative care should be holistic and person-centred, individuals are sometimes seen as asexual or not interested in sex or reproduction. They argue that practitioners sometimes forget to see the person, and only see the disease. They powerfully argue that:

> Failure to acknowledge [sexuality and fertility] in an individual in the palliative care context implies failure to acknowledge the person and thus, deny their personhood. (Higgins and Hynes, 2019, p. 5)

Third, although what it means to be an ‘adult’ cannot be universally described, and there is considerable debate in the literature on this, the markers of a normative transition to adulthood are often not met by those with life-shortening conditions. This means that transition to adulthood is problematic or not achieved with subsequent consequences for the way in which an individual is treated, and whether they are seen, by others, as an adult with the rights and responsibilities conferred by adult status. Life course theory (Elder *et al.*, 2003) refers to the way that people move into and out of transitional stages through their life and considerable attention has been paid to the transition of children and young people into adulthood. There are many markers of adult life including stages such as living independently, financial independence, moving from education into work, marriage, and parenthood (for example, see Shanahan, 2000). Many young adults with life-shortening conditions live with their parents or remain dependent on them for care. Education is often curtailed due to both acute and long-term illness, having a long-term impact on future financial independence. Moving into work is often not possible due to the curtailment of earlier educational opportunities and/or because of the nature of their condition, the associated symptoms and the medical regime required to treat it. Although these are not the only markers of adulthood, and other markers are important too, such as self-actualisation (du Bois-Reymond, 2016) the lives of young adults with life-shortening conditions are often qualitatively different to those of their peers.

In my previous research on young adults with life-shortening conditions (Earle and Blackburn, 2021) one participant – a competent and legal adult – highlighted the importance of being treated as such; this meant being allowed to make his own decisions and his own mistakes:

> ‘Over 18s are classed as adults so we should be able to be treated like adults, you know, and we have to make our own choices in life. We will learn from our mistakes, you know.’ (Participant 1 quoted in Earle and Blackburn, 2021)

The participants of this research project frequently described their experiences of infantilisation both within the home and in relation to their medical or social care. Other research (Steinberg, 2020) highlights how young adults with a variety of chronic conditions – who may not be able to accomplish ‘adulthood’ according to the normative markers that typically define it – seek to reject the process of infantilisation to construct an authentic adult identity despite the restrictions of their condition.

In summary, young adults with life-shortening conditions are especially vulnerable to a process of infantilisation which assumes they are childlike and, therefore, unable to take control of their own reproductive choices.

Imperative of moral responsibility

As I have argued elsewhere ‘disabled people are expected neither to reproduce nor be reproduced’ (Earle, 2001, p. 435) and so the reproductive futures of disabled people are positioned within a discourse of risk which determines that they **should not** responsibly reproduce. Reproductive loss is typically seen as a risk that should be managed and avoided (Martel, 2014). For disabled people, this creates an imperative of moral responsibility to manage sex and fertility and to avoid childbearing, both for the good of the individual(s), and for the greater good of society.

In the study by Blackburn (2019), a hospice nurse expresses the common ambivalence on the issue of whether young adults with life-shortening conditions should have children:

> *'Good luck to them if they want to parent.... but they and services need to remind themselves that inevitably they will die. The legacy will be in the child who is going to be born... Good on yah.... but some staff will have different views… some staff have iron rods up their bums and need to change their attitudes towards the sexuality of cognisant young people….'* (Primrose quoted in Blackburn, 2019, edited extract of original, p. 248)

Primrose considers herself to be supportive but suggests that other colleagues are less sympathetic to the needs of young people who want to have children. She highlights the challenges of fertility and reproductive loss for young people with genetic conditions which may be passed on to future generations and the role of reproductive technologies in managing this. She also highlights how service providers, and young people themselves, must consider the consequences of inevitable early parental death on any children that are born.

In the same study, parents of young people with life-shortening conditions expressed concerns about the potential impact of pregnancy on their child or child's partner and the possibility of having to step up to look after a grandchild should their son or daughter have children and then subsequently die. However, as Blackburn (2019) has pointed out, as yet there is no research exploring the experiences of parents who are in this position. Related research in the field of learning disabilities indicates that family members (especially grandparents) are often the main source of support for disabled parents and that while some family members are very encouraging of their children’s parenting ambitions, others strongly resist the idea (for example, see Gur and Stein, 2019).

For some people with life-shortening conditions, pregnancy and childbirth could have a deleterious effect on health and wellbeing, although the risks can often be managed or ameliorated. Changes in medical knowledge, treatment and care also change over time so what might be considered ‘impossible’ or ‘risky’ now may not be considered as such in 20 years’ time. In the interview with Chloe and Jordan, they highlight many of the ethical and moral complexities involved in this area, acknowledging how medical advances helped them achieve pregnancy. Chloe says:

> *‘I know for me ten years ago I wouldn't have been able to* [become pregnant] *and I'm so grateful for science for that. But one of the things they felt was very conflicting at the beginning was whether it was ethical to let me have a child knowing that I'd have to come off medication that would make me unwell. But also recognizing that I had the mental capacity to make that choice and if I wanted to make that choice that I was going to suffer…’* (Chloe, 2019, online)

It is interesting to consider how couples might negotiate issues of fertility and reproduction when one or both partners have a life-shortening condition. A close reading of the limited literature that exists suggests that there is a process of negotiation. For example, in Blackburn’s study (2019), a female participant, who is in a stable relationship and has decided that she doesn’t want to have children because of her complex life-shortening condition, describes the conversation she had with her partner about this:

> *'And we spoke about having children and Dee spoke to me about this. He said because I've got a life-threatening illness anyway. I said to him, "look, are we going to have children together?" He said, "look, I'd love to have children with you but I'd rather keep you". And he doesn't want to put me in more danger.'* (Jane quoted in Blackburn, 2019, edited extract of original, p. 246)

In the interview with Chloe and Jordan, it is clear they both want a child of their own and that they understand the risks involved. However, Jordan is also concerned and expresses some ambiguity:

> *'My one concern has always been, I want a family, absolutely 100%, but in a family, I still want my partner to be there at the end of it. I think my biggest dread was us having a baby and then me being left with the baby. Not because I'm not capable but it's the family unit, it's not me as an individual …'* (Jordan, 2019, online)

As illustrated above, reproductive decision-making is often negotiated but anecdotal evidence suggests that young adults with life-shortening conditions may sometimes feel coerced into making reproductive decision they do not really want or prevented from taking decisions that might put them at risk. For example, a woman might be prepared to take the risk of getting pregnant and bearing a child, but her partner won't allow it for fear of damaging her health or accelerating her death. The moral imperative to avoid having children means that issues of fertility and reproduction remain taboo and seldom discussed.

Conclusions and further reflections

As more children and young people with life-shortening conditions continue to survive into adulthood and their transition into adult life becomes the expectation rather than the deviation from what envisaged originally, issues of fertility and reproduction will become more urgent and important. Young people will expect more information and support particular to their individual needs and condition. Parents and carers are also likely to demand more information and advice, and delivered sooner, so that they can support their children. Professionals will require enhanced education and training that will enable them to address the needs of young people and their families and carers. These expectations will disrupt the normativity that currently exists: the assumption that young adults with life-shortening conditions can't, won't and/or shouldn't have children. There are of course some important caveats to bear in mind: First, not all young adults will be able to conceive their own biological children and/or will need assisted reproductive technologies and techniques to achieve this. Secondly, not all young adults will want to have children of their own, whether they are able to or not, biological, or otherwise. Any conversation on reproductive loss needs to reflect the heterogeneity of this group, as well as their experiences, needs and preferences as individuals.

With respect to the field of reproductive loss and life-shortening conditions, there are other aspects of this that I have not had the space to focus on here but are nonetheless important and part of wider scholarly debates concerning disability, and reproduction. For example, the experiences of parents with a prenatal diagnosis that is lethal or life-limiting (for example, see Blakeley *et al.*, 2019). Also, the subject of posthumous reproduction (the birth of a child after the death of a parent using advanced reproductive technologies) and the ethical, legal and communication considerations of this for palliative care (see Taylor, Moravek and Marks, 2022).

There is much we do not know about the expectations of young adults with life-shortening conditions and their experiences of fertility, reproduction, and loss. That which we do know suggests that their experiences are relatively poor and that their needs are not currently being met by practitioners and service providers, who themselves often feel ill-equipped to cope within health systems that are under-resourced and under-capacity (Blackburn, 2019; Earle and Blackburn, 2021). Parents, too, feel unprepared and unsupported (Blackburn, 2019). Although there is currently limited research, evidence suggests that earlier access to basic information about sex, fertility and reproduction is needed for all young people. Young people also need information that is specific to their condition and disability, including genetic testing and genetic counselling if needed. Overall, there needs to be more opportunities at home and in health and social care settings to talk about reproductive aspirations and expectations, and about feelings and experiences of reproductive loss, broadly defined. Healthcare environments and social care services also need to provide appropriate support that facilitates reproductive choices and gives young adults the time and space to discuss them. Better access to more specialist services (where needed) for IVF (in-vitro fertilisation) and similar treatments should also be available for those who want to explore this. There is scope for further research that builds on existing scholarly work to explore experiences of reproductive loss in more depth and to understand the meaning and consequences of this for young adults with life-shortening conditions.

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