

Chapter 3. *'I could cry all day, every day, about my losses':* Caring for young adults with life-shortening conditions – families' experiences of disruption and loss

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Abstract

Young people with life-shortening conditions were not expected to live into adulthood. However, changes to medical technologies and treatments mean that this 'new' population are now living longer than ever. This chapter is based on co-produced qualitative research carried out during the Coronavirus (COVID-19) pandemic which investigated the unexpected consequences of pandemic control measures such as lockdown and shielding. Using constructivist Grounded Theory Method, the chapter draws on interviews with family members who care for a child with a life-shortening condition. Four key findings emerge that highlight the disruption brought about by the material and anticipatory losses experienced by parents. These are: a loss of certainty and ontological security; the loss of idealised notions of babies and parenthood; the loss of future(s); and the anticipatory loss of an idealised good death.

Introduction

There are increasing numbers of young people with life-shortening conditions (LSC) who are now surviving into adulthood (Fraser, 2024). This is a heterogenous group with nearly four hundred diagnoses classified as either life-limiting (where there is no reasonable hope of cure) or life-threatening (where curative treatments may be feasible but can fail) in the UK (Noyes *et al.*, 2013). Some of these young adults live near-to-normal lives but more commonly live with episodes of acute illness, chronic pain, and disability; many also have associated cognitive impairment or developmental delay (Together for Short Lives, 2018). Young adults with LSCs often have high care needs, and many of them remain in the family home or rely on family for care. When a child is born with, or develops, a LSC during childhood or adolescence, family carers can experience both material and anticipatory loss. Drawing on a co-produced qualitative study of the experiences of young adults with LSCs and their families during the coronavirus pandemic (Earle *et al.*, 2022; 2024), this chapter focuses on experiences of care and loss among family members. Using an interpretivist approach, and constructivist Grounded Theory Method (cGTM) (Charmaz, 2006; 2014), we draw on thirteen interviews with family members, exploring multiple loss and the intersections between the biographical disruption of caring for someone with a life-shortening illness and the societal disruption of the pandemic response to coronavirus infection.

Background

The canonical concept of biographical disruption was developed by the sociologist Michael Bury (1982) to explore the experiences of adults diagnosed with rheumatoid arthritis. It is based on the fundamental idea that the onset of chronic illness is significant and disruptive; what Giddens (1979) terms a 'critical situation'. Critical

situations can threaten the ontological security of an individual. That is, the 'sense of continuity and order in events' of an individual's life (Giddens, 1984).

The concept of biographical disruption has been widely discussed and critiqued within medical sociology (e.g., Williams, 2000) and applied to multiple experiences of chronic illness, for example, childhood liver disease (Lowton, Hiley and Higgs, 2017), motor neurone disease (Harley and Willis, 2020) and severe sciatica (Saunders, 2018). Biographical disruption refers to the way in which illness is a disruptive experience with 'changes in life situation and relationships' (Bury, 1982, p. 167). Like Bury's original work, most of the research in this field has been applied to those who are chronically ill themselves and few scholars – this chapter being one exception – have focused on biographical disruption by proxy (e.g., see Raymond-Barker, Griffith and Hastings, 2018; Kingod and Grabowski, 2020; Rasmussen, Pedersen and Pagsberg 2020; Boardman and Clark, 2022). This is akin to Goffman's (1963) concept of 'courtesy stigma', stigma experienced by an individual through association with a stigmatised individual. This type of disruption has been described elsewhere as 'parent-biographical disruption' (Rasmussen, Pedersen and Pagsberg, 2020). Here – drawing on the notion of Goffman's concept of courtesy stigma, we use the term courtesy disruption to refer to the disruption experienced by parents through association with their child.

Life-shortening conditions are often characterised by their complexity, unpredictability and uncertain trajectory. The very fact that more children and young people with LSCs are now living into adulthood is illustrative of this and it is for this reason that policy imperatives encourage people with LSCs and their families to engage in 'parallel planning' (NICE, 2016). This refers to how family carers are encouraged to plan for the best (the continuing survival of their child), *and* the worst (their child's inevitable decline and death). Although considered good practice, the concept of parallel planning is not without critics, recognised as 'complex, uncertain [and] emotionally laden' (Morrison, 2020). To date, there is very limited empirical evidence on if, or how, parallel planning takes place in this context. We use the notion of courtesy disruption to inform our thinking about how family members experience caring for a child with a LSC and to consider how material and anticipatory loss feature in their everyday lives, from the point at which symptoms emerge, and a diagnosis is made, through to their child's eventual death.

Coronavirus (COVID-19) emerged sometime in 2019 and by March 2020 a pandemic was declared. In the UK, like in many other parts of the world, governments responded by introducing pandemic control measures such as movement restrictions and lockdowns (Lim, 2021). For those identified as 'clinically extremely vulnerable' – such as many people with LSCs – the government advised them to 'shield' (to stay at home and avoid face-to-face contact with others) in order to protect themselves, and wider society. The media began to widely circulate the information that 'only' older people, and those with pre-existing or underlying health conditions were at risk of dying from COVID-19 (Hastie, 2020). This served to reassure the general population that they were not at risk, while at the same time, positioning old, vulnerable and disabled people as disposable (Abrams and Abbott, 2020). During this time, the NHS also began to ration healthcare, using a Clinical Frailty Scale in a decision-making flowchart to assist clinicians in deciding who would be prioritised for critical care (Lewis *et al.*, 2020). Some young people and adults

with LSCs were advised by their clinicians that they would not be prioritised for emergency care, including critical care beds or ventilation (Earle *et al.*, 2022). As part of our study, we asked participants to tell us how pandemic control measures such as lockdown, shielding and the rationing of healthcare affected their everyday lives, including the ways in which they planned for the best, and the worst, for their child.

Methods

This chapter draws on a co-produced qualitative research study that set out to investigate the unintended consequences of pandemic control on the lives of young adults living with LSCs and their families in the UK. In total, 40 participants were recruited to the study but, as the focus of this chapter is on carers, only the data pertaining to the experiences of family members are presented here.

Design

Drawing on an interpretive philosophical framework (Kuhn, 1965) the study is informed by constructivist Grounded Theory Methodology (cGTM) (Charmaz, 2006; 2014). It was co-produced by a large multi-disciplinary team that included: three experts by experience (young adults with a LSC; 2 females; 1 gender non-binary), seven female academic researchers (four of whom also had clinical experience) and a policy expert.

Sampling and recruitment

Participants were recruited to the study between June and December 2020 using appropriate inclusion and exclusion criteria (see Table 3.1). In accordance with cGTM, purposive sampling was initially used to recruit participants before using theoretical sampling (Lincoln and Guba, 1985) to saturate emergent categories. We used a range of recruitment methods including advertising in the newsletters of the study partner organisations (*Hospice UK*, *International Children's Palliative Care Network* and *Together for Short Lives*), social media (e.g., Twitter) and the professional, academic, and social networks of the research team – the networks of the experts by experience were particularly helpful. All recruitment was carried out virtually given the need for social distancing and local lockdown rules.

Inclusion criteria	Exclusion criteria
Family member of person with a LSC	Not a family member of person with a LSC
Able to communicate in English	Not able to communicate in English
Able to give consent to participate	Not able to consent to participate
Able to participate remotely	Not able to participate remotely
Agree to be audio-recorded	Not agree to be audio-recorded
Living in the UK	Living outside of the UK

Table 3.1 Inclusion and exclusion criteria

Participants

We recruited 14 family members to the study; 13 were parents (12 mothers) and 1 was the partner of a young adult with a LSC. We draw here on the parent data only. Most of the family members were aged between their late 40s to mid 60s. All the participants were White, heterosexual and married except for one, who was divorced. Family members cared for young people and adults aged between the

ages of 14 and 34 who had a wide range of LSCs. Most of these young people/adults lived at home (n=9), two lived independently, and two lived in residential care local to the family member.

Data generation and analysis

Data were generated using in-depth interviews (Charmaz, 2014) informed by a topic guide which was amended as the research progressed (Charmaz, 2006; 2014). Online interviews were held between July and December 2020 on Zoom or MS Teams; they were all audio-recorded and transcribed verbatim with consent. Length of interviews varied between 76 and 116 minutes. Six members of the study team – four of the researchers, and two of the experts by experience – took part in interviewing. Interviewers sometimes worked in pairs either because they were not experienced researchers (the experts by experience) or had not previously carried out research with this population group (two of the four academic researchers).

Data were analysed inductively using the constant comparative method (Glaser and Strauss, 1967) and all team members participated in the process of analysis. Data analysis and theoretical sampling were carried out iteratively using line-by-line coding and memoing with the assistance of QSR NVivo 12. Coding was further analysed to generate core categories; some of these categories are represented in this chapter. We stopped interviewing when we had reached theoretical sufficiency (Dey, 2007).

Ethics

Ethical approval was given by The Open University Human Research Ethics Committee in June 2020 (#EARLE/3595). We followed the principle that research consent is a process that is constantly negotiated (Plankey-Videla, 2012) so all participants completed an online consent form and verbal consent was taken again informally during the research process. Participants could decline to answer questions on topics that made them feel uncomfortable and were able to stop or rearrange the interview at any time. All participants were followed up by email within 24 hours post-interview and sent relevant information about support services. Culturally appropriate pseudonyms were chosen to protect participant anonymity. All participants were offered an honorarium (£40 gift voucher) to thank them for their time and contribution to the study.

Findings

Four key categories were identified through analysis highlighting the courtesy disruption brought about by the material and anticipatory losses experienced by parents who care for a child with a LSC. These are: a loss of certainty and ontological security; the loss of idealised notions of babies and parenthood; the loss of future(s); and the anticipatory loss of an idealised good death.

Loss of certainty and ontological security

Life-shortening conditions can become apparent either before or when a baby is born – for example, through genetic testing, a problematic pregnancy, or complicated delivery. Other conditions become evident shortly after birth or in infancy and some develop later in childhood or in adolescence. Family members begin to experience

the loss of certainty and ontological security at different times depending on when their child showed symptoms of, or was diagnosed with, a LSC.

Mary's son, Oliver, has a medically complex and rare genetic syndrome. Shortly after he was born, she was told that he probably would not live beyond his first year of life:

... the first year of their lives a 95% death rate, but as he's got older obviously he's got better... we were told Oliver was a no hoper, and that they probably didn't think he would survive. [Mary, in her 50s, mother to Oliver, mid teens]

In contrast, in David's case, his daughter Tabitha, who is now in her early 30s, lived a relatively normal life until her late teens and it was then that symptoms emerged:

I mean this started probably when she was 17... and from then on the difficulties set in as we tried to understand what happened to this erstwhile very fit and still very bright girl as to what the bloody hell's gone on. I guess the first eight or nine years, it was just trying to sort the procedural stuff out because we didn't know what was wrong with her and then we did know what was wrong, we didn't know what to do with that diagnosis. [David, in his 60s, dad to Tabitha, mid 30s]

David describes how they 'lurched from specialist to specialist' until – many years later – a diagnosis was given. In some instances, a diagnosis can have repercussions for other children within a family. For example, when Tina's daughter, Patsy (now aged 30), was diagnosed with a LSC in her 20s, this meant it 'then gave the diagnosis to her sister as well'.

Following diagnosis, the prognosis of many LSCs is typically evolving and ambiguous and, in some cases, symptoms are not definitively diagnosed, leading to ongoing uncertainty, sometimes for the duration of a child's life. Family members often use familiar tropes and illness metaphors to manage and describe the ongoing but uncertain survival of their children:

His prognosis was very poor, in as much as they thought that if he did well, children like this who do well survive to puberty, and he's 29. So like a lot of our young people, he's beaten all the odds. [Barbara, in her 60s, mother to Kevin, late 20s]

Initially they thought that her life expectancy would be around 12 and then they said maybe 16 or 17. So for us to get to 22 is just a miracle really... So, she's a real toughie and a real fighter. [Lynne, in her 60s, mum to Belinda, early 20s]

So, she's had quite a few close shaves, I think she's a cat with nine lives, but she's rapidly running out of them... [Erin, in her 50s, mother to Clara, early 30s]

The loss of certainty and ontological security begins with the diagnosis of symptoms that are recognised as life-shortening, even when achieving a diagnosis takes many years, if at all. The uncertain prognosis that is typical of many LSCs extends this

uncertainty throughout a child's life, and can have unsettling implications for others, such as siblings.

Loss of idealised notions of babies and parenthood

When a child is diagnosed with a LSC, family members begin to experience the loss of idealised notions of babies and parenthood. This type of loss speaks to the way in which expectant parents imagine their future child, their relationship with that child and the life they will share both together and separately.

Lynne spoke about the loss of her imagined future with a new baby and the grieving process when her baby was technically stillborn and then survived. She describes her daughter, as '*medically complex, profoundly severely disabled, with severe learning disabilities and a diagnosis as long as your arm*':

You know, when you're pregnant you have all these wonderful plans about what you're going to do with your baby... So when we had Belinda obviously those plans were completely shattered... I could sit and I could cry all day every day about my loss. Because I guess in some ways Belinda was born and she wasn't what I thought she was going to be so it's a grieving process isn't it. But she's an absolute blessing. [Lynne, in her 60s, mum to Belinda, early 20s]

Like many family members, Lynne describes a deep loss on learning that her child would be profoundly disabled but – at the same time – is keen to emphasise the positives, describing her daughter as a '*blessing*'. Other participants made similar comments, for example one described her son as '*one of the happiest people I've ever met*' and another reflected on how her '*life would be weird without*' her son.

Many family members spoke about the impact of their child's illness on their own lives, particularly the impact this had on work and careers. Some participants gave up work temporarily to care for their child, before later retraining and returning to the workforce. Others simply gave up work to care for their child on a permanent and full-time basis, for example, Doris says:

I had to be medically retired when my daughter was five when she had cancer the second time because I needed to look after her. So, I got medically retired from my job and I've cared for her ever since. [Doris, in her 60s, mother to Henrietta, late 20s]

All family members provided care for their child, even when that child was living outside of the family home. This caring role made it difficult for some participants to identify with a parenting (mothering) role. For Lily, it is her relationship with her other (non-disabled son), John, which enables her to fulfil her mothering role, describing themselves as '*best of mates*':

I've got a 28-year-old, John. To me he feels like an only child... You know, I don't feel like mum half the time with Elena, I feel like carer. Whereas with John I'm mum all the time. No matter what happens I'm still mum.... It's mum and son. Best of mates. [Lily, in her 40s, mother to Elena, early 20s]

In contrast, some family members struggled to identify as carers. Erin, for example, whose daughter lived independently, saw herself simply as a mother:

I'm just her mum... so we've got this carer's group in work and no I don't, because I'm just doing what your mum does. Yeah, it's stupid I know, I know that's actually what I am [a carer], but yeah. It's complex... how do you unpick that relationship between mum and being a carer? [Erin, in her 50s, mother to Clara, early 30s]

One family member – David – rejected the carer role, expressing ambivalence about what it means to be 'a carer'. It is interesting to note that David is the only father within the study:

I said to my wife when we realised that she was going to need care long term that I was not a carer, but I was her father. And she sort of baulked at that. [David, in his 60s, dad to Tabitha, mid 30s]

Trajectories of biographical disruption differ depending on when it becomes apparent that a child has a LSC. In some cases, it is immediately apparent that a child will have complex needs and in others, symptoms begin to emerge later. This unexpected change to an idealised norm of babies and parenting serves to disrupt plans and hopes for the future including the disruption of parental identities.

Loss of future(s)

Following the diagnosis of a LSC, family members typically describe the trajectory of their child's life as 'unknown'. This uncertainty, together with the expectation of parallel planning – planning for the best, while preparing for the worst – is disquieting and makes it difficult to look to the future.

We asked family members to tell us about their experience of parallel planning. Some family members recognised that the early death of their child was inevitable, even if it was something that they chose not to dwell on often. Like most participants, David found the subject difficult to talk about:

The fact is that she has a much higher chance of early death, maybe dying before I do... And that's difficult, but that's life, or indeed, that's death. And you can't go down the rabbit hole of 'why has it happened to my daughter?'... That's not the way to handle it, you can't do it. [David, in his 60s, father to Tabitha, mid 30s]

Several participants said that they had not discussed parallel planning at home. A reluctance to talk about end-of-life was typically framed within the context of their child being 'really well', or 'doing OK', thus minimising the need to talk about death. For example:

[This is] not something we discuss. Even in our house, we don't discuss that. God forbid that ever happened. But Oliver seems to be doing OK. [Mary, in her 50s, mother to Oliver, mid-teens]

Some families talked about having advance care plans, although they saw it as something that had been ‘done’ (and put away) rather than as an ongoing process. In several instances, advance care planning had been undertaken as part of the transition from children to adult services and, since that time, had not been revisited. Michelle said:

No, nobody’s ever mentioned it [advance care planning] since we stopped using the hospice... I don’t know, I think it’s, sometimes we almost have to remind ourselves that Ian’s got this condition, because during the day when he’s up and about he does lead an almost normal life... I’m not sure if that’s irresponsible or not, I don’t know. [Michelle, in her 50s, mother to Ian, early 30s]

At times – particularly at a time of crisis – revisiting parallel planning comes to the fore. At the time of interview, Rachael’s son, Anthony, was having an emergency brain scan, following chemotherapy treatment for a renal tumour:

I struggle with the advanced care directive, end-of-life stuff obviously, but we have to think about that. It could be a discussion I’m having tomorrow afternoon with his neurologist again... I just try not to visit it too regularly for my own sanity, but it’s always there. [Rachael, late 40s, mother to Anthony, early 20s]

Overall, most participants avoided dwelling on the likely early death of their child and preferred to focus on more immediate concerns. For example:

Well, honestly, we don’t look that far ahead. I would say I look five years ahead with Finnley... Looking at the future that far ahead does scare me. [Tabitha, in her 50s, mother to Finnley, late teens]

The pandemic accentuated the tendency to focus on living in the moment, rather than thinking about an uncertain and undesirable future. For example:

I think it’s underlined my thinking that you have to live for the moment. You can’t plan too far ahead... So yeah, I think that’s, it’s a message for us all isn’t it? [Rachael, late 40s, mother to Anthony, early 20s]

The ongoing uncertainty of caring for a child with a LSC meant that looking to the future was difficult and, often, avoided. The findings suggest that some family members had engaged with parallel planning, but many found it difficult to talk about. The pandemic heightened a sense of living in, and for, the moment against the threat of potential COVID infection.

Loss of an idealised ‘good death’

Although family members found it difficult to talk about the death of their child and most avoided discussion of parallel planning, it was clear that the majority had given some thought to how and where they would like their child to die. During interviews we asked participants to talk about the effect (if any) of the pandemic on their end-of-life planning. It was clear that the pandemic was disrupting this, although not everyone wanted to consider it. For example, one participant said:

I haven't even thought about it because I couldn't bear to think about it. It would be horrendous. [Doris, in her 60s, mum to Henrietta, late 20s]

Although participants recognised that the death of their child was, eventually, inevitable, dying from COVID was seen as preventable and avoidable. Lily says:

I think my biggest fear has always been, with Elena, losing her to something that I can prevent. If I can prevent it, there's no need for it to happen. [Lily, in her 40s, mum to Elena, early 20s]

Like Lily, Lynne was focused on keeping her daughter safe and did not want to consider the need for alternative end-of-life plans:

I'm here to keep Belinda safe. So, I just have got in a complete mindset of this is our life, this is what it is at the moment... This is the way that I'm keeping Belinda alive... So, this, as far as I'm concerned I have no alternative... I've just dug deep and get on with it. [Lynne, in her 60s, mum to Belinda, early 20s]

Family members were aware that COVID restrictions might impact on end-of-life plans and that options previously available to them might not be. They were also aware of the prioritisation of healthcare within hospitals, particularly access to ventilation and critical care. For example:

I think to start with we were all very worried for him, because what the doctor said made perfect sense. That they wouldn't ventilate Anthony and they didn't think his lungs and kidneys would cope. [Rachael, in her 40s, mother to Anthony, early 20s]

It was difficult in the beginning, because NICE were thrashing out these guidelines, weren't they? There was the frailty scale, you know, if there was a shortage of oxygen... if the hospital is overloaded, then Ewan being in the state he was, they wouldn't have taken him in. [Bronwyn, in her 50s, mum to Ewan, late teens]

Participants were particularly fearful of the idea that – because of COVID restrictions – their child might die alone. Jessica's response was typical of this:

I think my main thing is that if she did get ill and she was in hospital, I would be absolutely insistent that she was never on her own. I'd stay with her 24 hours if I had to. [Fiona, late 40s, mother to Jessica, late teens]

Barbara's son Kevin lived in residential care. Like other family members, she wanted her son to die in a familiar setting and was surprised that the care home would choose to send her son to hospital where he would be isolated and alone:

If he was to become ill with COVID and our discussions at the time was not to be admitted, not to be ventilated, not to be separated from the family but to be given palliative care... And then I talked to the manager of the care home...

who was all a bit shocked and said 'well, obviously if he gets ill he'll go straight into hospital'. I said 'I don't think that's how it's going to work'... we don't want him to be there isolated, scared, completely cut off on his own. [Barbara, in her 60s, mother to Kevin, late 20s]

In the following extract Lily expresses real ambivalence about what she wants for her daughter, Elena, should she become unwell. On the one hand, she wants her daughter to survive but does not want her to die alone.

...it's written everywhere for everybody wherever she goes, if she suddenly stopped breathing you keep her alive until I get there. Because I do not want her to pass without me being there, I need to be with her... she'll be staying here. She will die here where she knows everyone. Yeah, she won't be dying anywhere else. [Lily, in her 40s, mum to Elena, early 20s]

Although family members found it very hard to talk about the subjects of death and dying, they had developed the concept of a good death for their child. For many, the disruption brought about by the pandemic threatened this concept and led to fear and uncertainty about what might happen. For others, the focus was on keeping their child safe through the pandemic and could not bring themselves to think about losing their child to something they regarded as preventable.

Discussion and conclusion

This chapter has explored the material and anticipatory losses experienced by family members who care for a child with a LSC and the way in which some of these losses are amplified by the pandemic. At the time the interviews took place, the pandemic control measures predominantly appeared to impact on concerns around planning for end of life and what might be feasible in relation to a good death given the controls in place in hospitals and hospices.

When a child becomes ill and is then diagnosed with a LSC, family members experience a disruption to their ontological security (Giddens, 1984). That is, they no longer have the stability and certainty they once had prior to the disruption brought into their lives by their child's illness. Bluebond-Langner (1996) describes this as living in the 'shadow of illness', something that can also affect others, such as siblings. However, our study highlights how family members, in the context of the loss of certainty and ontological security, also seek to normalise their experiences and find the positives amidst the disruption of life-changing illness.

Life-shortening conditions are often in flux, characterised by periods of stability, followed by episodes of acute illness, including life-threatening events. The loss of certainty and security can be gradual or immediate, depending on when and how symptoms emerge, and (whether) a diagnosis is made. This uncertainty leads to a form of courtesy disruption, or parent-biographical disruption (Rasmussen, Pedersen and Pagsberg, 2020), which threatens the identity of family members and the imagined future(s) for themselves and their child. The loss of idealised notions of babies and parenthood can, however, come to be replaced by a carer identity, although this is not uncomplicated.

Our study shows how family members often describe the trajectory of their child's life as '*unknown*' and most were mindful of the need to plan for the best, *and* the worst, for their child. The 'parallax' (Žižek, 2006), a concept used by MacArtney *et al.*, (2017) to describe both the liminality and positive actions required to navigate living and dying at the end of life, is useful here. Most family members found the idea of parallel planning very challenging. Some research participants did not want to talk about it, and became pensive and tearful during interviews, although all of them were willing to discuss the topic with us when prompted. Although family members were resistant to the idea of advanced care, or end-of-life planning, the pandemic underlined the importance of this but made them fearful for the life, and death, of their child.

There is a considerable body of literature on the notion of a 'good death' (see Kellehear, 1990) and it is a central tenet of the hospice movement (Hart, Sainsbury and Short, 1998). The good death has been subject to considerable criticism but holds a diversity of meanings and interpretations. Pandemic restrictions and the threat of COVID-19 threatened participant's plans for a good death and ensuring that their child did not die alone was prevalent across accounts. Although early death is non-normative, parents of children with a LSC develop a new normal; that their child will die, eventually, from their condition and this forms part of a revised normality, integrated into their biographies. The possibility of dying from COVID disrupted this new normal; it was seen as unacceptable and regarded as a preventable, bad death.

All research studies have strengths and limitations. We felt fortunate to interview participants about their experiences of everyday life during the pandemic, at a time of considerable personal and social crisis and uncertainty. To our best knowledge, it is the only co-produced qualitative study of its kind in the UK during the pandemic. However, our study group was predominantly female, heterosexual and White meaning that some groups are not well represented within the data.

This study is not exhaustive in its analysis of the courtesy disruption and material and anticipatory losses experienced by family members who care for those with a LSC. Greater attention to gender, disruption and loss would be advantageous as would a focus on non-White populations, especially since epidemiological studies suggest that the prevalence of such conditions is highest among young people of Pakistani, other Asian and Black origins (Gibson-Smith *et al.*, 2021).

Acknowledgements

Thank you to our research participants and to the late Lucy Watts, who also contributed to this project.

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