



Nottingham Trent
University

Sex, danger and vulnerability: young adults living with life- shortening conditions

Professor Sarah Earle

A 'new' population

Young adults who were not expected to live

- Diagnosed at birth or during adolescence
- Terminology varies internationally but there are nearly 400 individual diagnoses
- Medical treatment and care has transformed life expectancy for some
- No of life-limiting conditions as risen over time and is rising
- In UK prevalence is higher in people of Pakistani, other Asian and Black origins
- In UK young adults with LSCs more likely to live in areas of deprivation.

Vulnerability

(and resistance)



“

Resistance discourses challenge mainstream notions of disability and sexuality and combat the oppression that ableism and sexism can create. It is important to highlight these resistance narratives; they are often overlooked in society.

MacKeigan, 2021, p. 656

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Narratives of vulnerability

Being vulnerable means that bad things are more likely to happen to you.

Young adult voices

(Health and wellbeing research project)



a reason to live





Eddy: Relationships give you a reason to live and fight on.

Nadir: They give you a reason to live – they make you happy.

Eddy: They keep you wanting to live.

Eddy & Nadir, male, group 3



normative expectations



[Relationships are] pretty important. Most people expect it.

I: Who?

Society – it's like a rite of passage.

I: Why is it important?

Dunno, you hear stories of people around 40 who aren't married, people think they're weird.

Eddy, male, group 3



“

I'm not going to lie, in our culture, it is literally if you're not married by 25, people think there's something wrong with you, literally I'm not joking... it's kind of hard.

Nasrin, female, group 4

”

learned vulnerability



“

*They were on about us being extra vulnerable...
It's quite scary to be honest, when they say you're
vulnerable, because you don't think of yourself as
a vulnerable person, until someone says it.*

Harriet, female, group 2

”

“

... because people are protective of me, that's made me feel more vulnerable. If they were like, 'oh, you're fine' then I would be, I'd feel fine. But because they're always too over-protective it makes me feel like I need to be more [careful].

Bethany, female, group 2

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Invisible and asexual





If they think you're vulnerable, or you need help or protecting then nothing will happen. You want someone who, like, doesn't see the disability or the wheelchair. You want them to see you.

Kamil, male, group 1



danger and risk





I've had a friend who, he broke up with his girlfriend because he was seriously ill in hospital and she couldn't cope with it.

Tom, male, group 1





If you tell too much to one person people might take advantage of you because you have a disability.

Maria, female, group 4



“

My parents won't let me go online because you might meet someone online and you may get a shock because they aren't who you think they are. Mum and Dad won't let me do things like that because I've had brain tumours - that's had an effect on everything.

Liam, male, group 5

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“

My parents would be anxious someone might hurt me.

Elliot, male, group 5

”

“

I used to think of the future and whatever, but I don't want to think about it, because if it doesn't happen then I'm going to be sad because I wanted it to happen.... that's completely put me off. I don't aspire to anything anymore.

Jane, female, group 4

”

Commentary and implications

- Narratives of vulnerability must be heard alongside stories of power and resistance.
- Vulnerability is ascribed by others and assumed to be inherent
- Vulnerability is learnt, internalized and enacted
- Ascribing vulnerability has ongoing consequences for living a full life
- Adults, including parents, professionals and policy makers should provide young people with the tools to minimize harm

Project publications

1. Earle S (2024) Disrupting normativity: Understanding reproductive loss in the lives of young adults with shortened lives. In: Earle S and Blackburn M (eds) *Sex, Intimacy and Living with Life-Shortening Conditions*. Routledge, London.
2. Earle S, Blackburn M, Chambers, L, Downing J, Flemming K, Hale J, Marston H, O'Dell L, Sinason V and Whitney S (2024) Disruption, Relationships and Intimate Futures: The unintended consequences of pandemic control. In: Earle S and Blackburn M (eds) *Sex, Intimacy and Living with Life-Shortening Conditions*. Routledge, London.
3. Earle S, Blackburn M, Watts L and Whitney S (2024) Involving Young People with Life-Shortening Conditions in Research: A conversation on the politics of co-production methods. In: Earle S and Blackburn M (eds) *Sex, Intimacy and Living with Life-Shortening Conditions*. Routledge, London.
4. Earle S, Blackburn M, Chambers, L, Downing J, Flemming K, Hale J, Marston H, O'Dell L, Sinason V, Watts L and Whitney S, (2022) 'Whose life are they going to save? It's probably not going to be mine!' Living with a life-shortening condition during the Coronavirus (COVID-19) Pandemic: A grounded theory study of embodied precarity, *Qualitative Health Research*. <https://doi.org/10.1177/10497323221131692>
5. Earle S and Blackburn M (2021) Involving young people and adults with life-limiting conditions in research on sex: The intersections of taboo and vulnerability, *International Journal of Social Research Methodology*, 24:5 545-551. <https://doi.org/10.1080/13645579.2020.1857968>



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Thank you

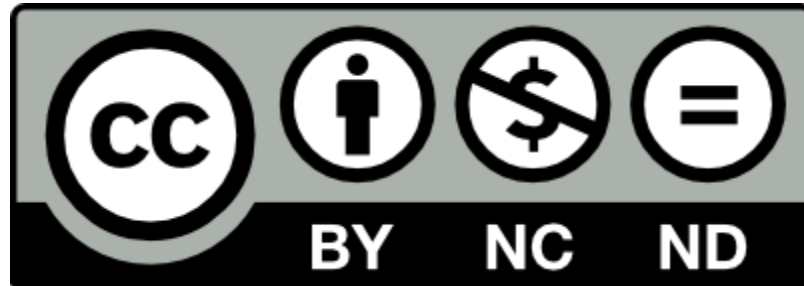
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