Distancing, PPE, and moral distress in England's hidden care landscape

STAY ALERT ▸ CONTROL THE VIRUS ▸ SAVE LIVES

HANDS FACE SPACE

STAY HOME ▸ PROTECT THE NHS ▸ SAVE LIVES

Andrea Lambell BSc (Hons), MA

andrea.r.lambell@durham.ac.uk

Department of Anthropology

ICMI, 9 April 2024

UK RI
Economic and Social Research Council

NINE DTP

Durham University

People's pandemic stories

Online survey

August-October 2020: n=464

Over 80% had given and/or received health and/or social care in the presence of PPE and distancing

Interviews

All had given and/or received care

September-December 2020: n=33

of whom, 9 were re-interviewed between March and May 2022

Image: Luke Jones on Unsplash

"I'm not his carer, I'm his wife!"

Dave, GP practice manager

Content:

- England's hidden care landscape

- Carers' experiences of PPE and distancing

- Experiences in the context of Potential Morally Injurious Events (PMIEs)

Image: Jack Finnigan on Unsplash

Definition of an unpaid carer:

A person who looks after a family member, partner, or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.   (NHS England)

The value of care

Estimated economic value of unpaid carers, England and Wales, 2021 **= entire NHS budget**

Unpaid carers save the public purse **£18.6 million per hour**
(Petrillo & Bennett, 2023)

Carer's Allowance: can be claimed by people who have more than 35 hrs/week caring responsibilities. Must meet other strict criteria (e.g. cannot be a student or a pensioner).

£76.75 a week = 46p an hour for people caring 24/7 (DWP, 2023)

Unrecognised carers

It takes an average of two years for a person who has taken responsibility for caring duties to see themselves as a 'carer'   (NHS England)

Epistemic injustice, *'a wrong done to someone specifically in their capacity as a knower'* (Fricker, 2007), translates into **moral injustice and moral distress** (Reed & Rishel, 2015)

Hermeneutical epistemic injustice: when someone's experiences are not well understood, by themselves or by others

Image: Adrian Swancar on Unsplash

Testimonial epistemic injustice: when prejudice causes a hearer to give a deflated level of credibility to a speaker's word

'I don't think the family carer did get much of a mention at all, and they were providing a lot more care than anybody else'

Paula, carer support worker

'Institutional distancing'

Image: Nick Fewings on Unsplash

The disconnection between people and care infrastructures

A form of **structural violence** (Galtung, 1969; Farmer, 1996):

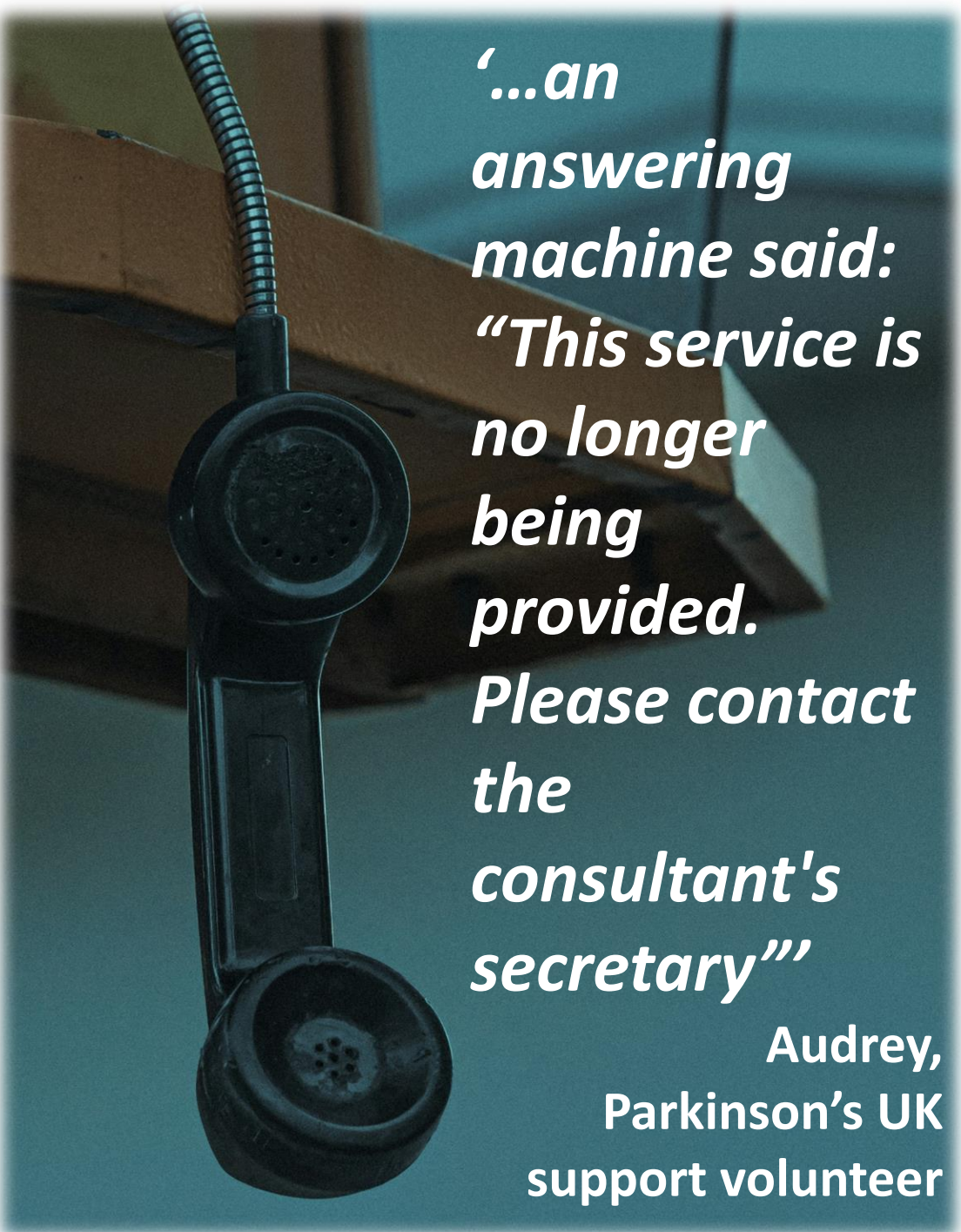*'social arrangements that put individuals and populations in harm's way'*

- Pre-existing
- Pandemic-related

Pre-pandemic care landscape

Austerity: Loss of services in 2010s

'Responsibilised commoditisation': family members' sense of responsibility is utilised by the state as a cost-saving alternative to investing in services (Higgins & O'Leary, 2023)

'*...an answering machine said: "This service is no longer being provided. Please contact the consultant's secretary"'*

Audrey, Parkinson's UK support volunteer

Image: Önder Örtel on Unsplash

Carers' pandemic dilemmas

Support withdrawn: Day services and respite shut down. No alternative offered

PPE shortages: Risky equipment-sparing behaviours by domiciliary care workers who had multiple contacts

Lockdown: Asking for help from other households prohibited

Impossible choice: Tolerate "superspreader" care workers in my home, or do it all myself 24/7

The 24/7 experience

'...he was being violent and going for her. And they got him into a ward and they said: "Oh, he's fine, he's coming home", then he went for one of the nurses ...but he's back at home again'

**Laura,
Parkinson's UK support volunteer**

Image: Ani Kolleshi on Unsplash

Family or clients?

'When it hit really bad at the homes I thought: "I'm going to have to stop going to see my grandma here, I'm going to have to literally tell her I can't come and assist her"... I was frightened for my own family, which I found really selfish'

Alex, care home manager

The Cummings effect

A loss of trust demonstrating how dangerous "leader exceptionalism" can be for collective citizenship and social unity

(Fancourt, Steptoe, & Wright, 2020)

'…they were saying, "We haven't been to see our parents, and they need us. But he can do it. So bugger it"'

Paula, carer support worker

2 METRE GAP

No way out

'...there's a lot of people that have had to really consider their employment – how they work, can they actually work? – because of the role that they've now inherited due to Covid'

Liz, carer support worker

Thank you.

Any questions?

Image: Nick Fewings on Unsplash

References:

Department for Work and Pensions (2023) *Benefit and pension rates 2023 to 2024.* 28 June. Available at: https://www.gov.uk/government/publications/benefit-and-pension-rates-2023-to-2024/benefit-and-pension-rates-2023-to-2024 [Accessed 2 January 2024]

Fancourt, D., Steptoe, A. & Bradbury, A. (2022) *Tracking the Psychological and Social Consequences of the COVID-19 Pandemic across the UK Population: Findings, Impact, and Recommendations from the COVID-19 Social Study (March 2020 – April 2022).* Available at: https://www.covidsocialstudy.org/_files/ugd/064c8b_fa25a87fd1ba4e99b7d069e7af76c64a.pdf [Accessed 30 September 2022]

Fancourt, D., Steptoe, A. & Wright, L. (2020) 'The Cummings effect: politics, trust, and behaviours during the COVID-19 pandemic', *The Lancet*, 396(10249), 464-465. doi: 10.1016/s0140-6736(20)31690-1

Farmer, P. E. (1996) 'On suffering and structural violence: A view from below', *Daedalus,* 125(1), 261-283. Available at: https://www.jstor.org/stable/20027362 [Accessed 5 March 2020]

References:

Fricker, M. (2007) *Epistemic Injustice: Power and the ethics of knowing.* Oxford: Oxford University Press.

Galtung, J. (1969) 'Violence, peace, and peace research', *Journal of Peace Research,* 6(3), 167-191. Available at: https://www.jstor.org/stable/422690 [Accessed 7 January 2020]

Higgins, L. & O'Leary, K. (2023) 'Clap for "some" carers': Problematizing heroism and ableist tenets of heroic discourse through the experiences of parent-carers', *Marketing Theory,* 23(1), 11-32. doi: 10.1177/14705931221123991

NHS England (n.d.) *Who is considered a carer?* Available at: https://www.england.nhs.uk/commissioning/comm-carers/carers/ [Accessed 2 April 2024]

Petrillo, M. & Bennett, M. (2023) *Valuing Carers 2021: England and Wales.* London: Carers UK. Available at: https://centreforcare.ac.uk/wp-content/uploads/2023/05/Valuing_Carers_WEB2.pdf [Accessed 24 March 2024]

Reed, P. G. & Rishel, C. J. (2015) Epistemic Injustice and Nurse Moral Distress: Perspective for Policy Development. *Nursing Science Quarterly,* 28(3), 241-4. doi: 10.1177/0894318415585634