

Dr Kathryn Hinsliff-Smith

Associate Professor

*Deputy Director Institute of Health, Health Policy
and Social Care Research, DMU*

 **@Hinsliffk**

Kathryn.hinsliff-smith@dmu.ac.uk

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Presentation Title

We went from understanding, to disappointment, resentment and often grieve all in the space of 6 months. The stories of family carers for care home residents during the pandemic in 2020

Study: The experience of family carers and keeping in regular contact with loved ones who permanently live in a care home during the COVID-19 Pandemic, a UK perspective

October 2021

P R O U D T O B E M O R E

The care home sector in the UK

- In the UK around 450,000 people live in long term residential and nursing homes (Laing & Buisson, 2010).
- This is a bed base three times that of the acute hospital sector in England (Ewbank et al., 2020).
- Most are aged over 80, many with a cognitive impairment including dementia related conditions as well as multiple co-morbidities (Gordon et al., 2014).
- In the UK our care home provision is now predominately privately owned, operated by companies or individuals, chains of care homes, charities/religious organisations and a few operated by a local public authority
- Care homes in the UK are funded entirely differently from the National Health Service (NHS).
- There are around 19,000 independently owned care homes in the UK

Covid-19 Global response and UK Government response

The World Health Organisation (WHO) declared that the outbreak of COVID-19 constituted a Public Health Emergency of International Concern (PHEIC) on **30th January 2020** (ECDC 2020). It was classed as a pandemic on the **11 March 2020**.

On the **23rd March 2020** the UK population was advised,
to stay at home, protect our NHS and save lives

Study design

- This was a UK wide qualitative empirical study focusing on family carers who pre COVID regularly visited their relative (at least 3+ times per month)
- ***Our planned*** data collection involved interviews (up to 5 planned per participant) ***over the period of post lockdown and into 'normal' visiting***
- A topic guide was used to elicit responses from participants
- We had 13 consented family carers and conducted a total of 27 interviews
- Our 1st interviews were conducted in June/July 2020 and into Sept/Oct 2020 and were planned around key milestones for the relative/resident or guidance/policy

[Study details](#)

Pre-COVID - How visits were constructed



- Lengthy and regular
- Engaged in different social activities
- Sustained over a period of time
- Provided care and mental stimulation
- Positive relationship with care home and staff
- Felt valued by the care home



Pre-COVID - How visits were constructed

Example: Feeling part of the care home community:

*“And I have to say XXXXXXXX because we were there so much the residents **became like an extended family**. They were part of my mam’s and dad’s community in the town we lived in xxx it was very much part of our community now. **So they became our friends and the staff did as well**. Urm ur you know very realistically obviously they weren’t you know **family members** but they did with myself and my sister wrapped themselves around the care of my mum” PT10*

Pre-COVID - How visits were constructed

The routine:

*“So that’s what I did **literally Monday to Friday every night for the last two and half years**” P10*

*“I **cycle every day** to see my Mum, its not far, the next Borough” P2*

*“I go **nearly everyday** by public transport” P8*

Three Overarching Themes

Theme 1 - Understanding and Acceptance

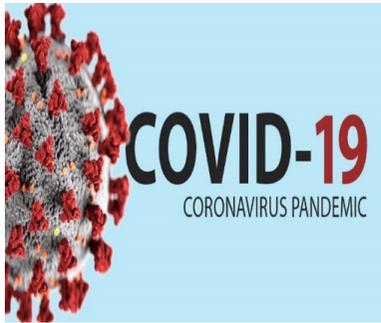
Theme 2 - Disappointment and Resentment

Theme 3 - Grieve and Sense of Loss

These extracted themes strongly relate to the different periods of the UK lockdown, opening up of society and changes in policy and guidance.

Theme 1 - Understanding and Acceptance

- June and July 2020 8+ weeks into the Lockdown



- Most participants anticipated a lockdown and restricted visiting
- In most cases it was an informal notification of the restriction
- Fully supported and felt it was for the good of the residents - they needed to be protected – it was the unknown
- It felt inline with the UK wide lockdown

*“the receptionist I know very well. I hadn’t gone on the Friday..... she called me she said where are you I said oh I’m in Costco, I was getting my loo rolls and stuff and she said **we’re going to close down** and so I dashed their to mum I mean there’d kind of been murmurings that we will be closing down” PT13*

*“they said towards the end of the week this was the Monday by the end of the week they were going to make the decision so I was aware you know but **not that it was going to happen that day**. If I’d known about it I would have you know stayed a bit longer sorted something out. **I would have been in my head been prepared.***

*When it came up I was just devastated and then of course your head starts playing tricks when will I get to see him you know.
I found that really difficult” PT8*

Theme 2 – Disappointment and Resentment

- During the summer of 2020 lifting of some restrictions



Theme 2 – Disappointment and Resentment

- During the summer of 2020 lifting of some restrictions

*“Mum’s trying to touch my face you know. And she can hear me but obviously everybody’s **wearing masks**” PT13*

*“Upsetting really you know the fact that he was so close and I couldn’t touch him. We’ve had **video calls throughout you know the lockdown** but its really difficult again because he really doesn’t understand what’s going on obviously he sees my face on the screen and its just like sort of you know its been tough. Its better to see him in the flesh but it looks like he’s shrunk a bit (laugh)” PT8*

*“As far as contact with my mother I have been able to speak to her on the **mobile phone** the conversations are short and it depends **upon what carer she is with** as to how they handle the call with her because she needs to be directed in holding the phone” PT2*

But there were positive accounts of communication:

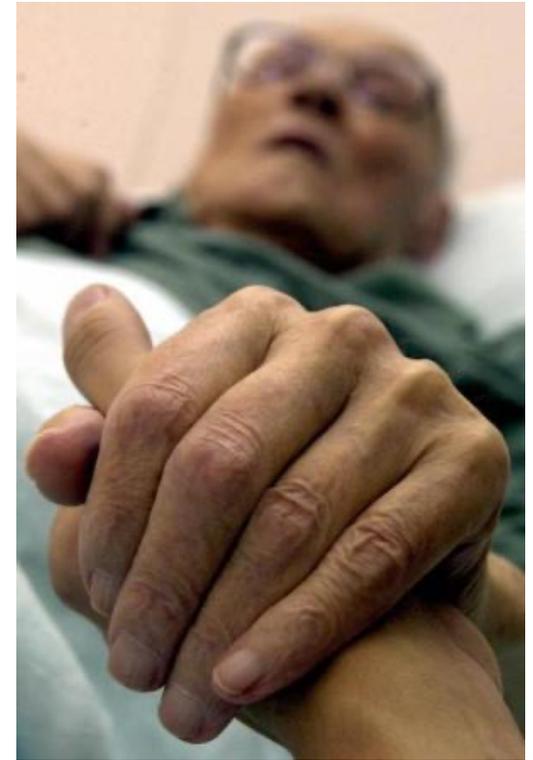
*“We were getting regular updates from the care home they were telling us that they were **COVID free and they continued to be COVID free**” PT10*

Theme 3 - Grieve and Sense of Loss

- still with some restrictions in place and uncertainty about winter visits 2020



- **Increased levels of anxiety - similar to locating a care home initially**
- **Feeling powerless/sense of loss**
- **Concerns that they may not get to see their relative again**
- **Concerns about overall health and mental well-being of residents**



Thank you

Thank you on behalf of the research team and special mention to all our participants who gave their time and voice freely

 **@Hinsliffk @Jayne_NurseProf @SarahCGriffiths**

Study Team at DMU

**Dr Kathryn Hinsliff-Smith, Dr Sarah Griffiths,
Prof Kay deVries, Prof. Jayne Brown,
Wendy Padley**



I now have pleasure in introducing our
Canadian colleagues

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