'Informal families like ours seemed unaccounted for'

Pere Blaney is a mature psychology student and father caring for three children of family/friends. These children are now adults – Max aged 22, Luke aged 25 and Joe aged 28 – living in their own homes, but experiencing mental health difficulties every day. Sam's house was their sanctuary away from the destructive nature of their conditions, a home with love, support, and mental health care daily… until Covid-19.

When Covid-19 struck the world, it was terrifying – a disease could kill my family. The government released lockdown restrictions to protect the public. However, Covid wasn't the only danger. In one moment, my family could, by law, no longer spend time together at my house. The foundations were ripped from under us. Restrictions allowed single-parent families to meet, but informal families like ours seemed unaccounted for, prevented from providing essential care.

We live independently, but our support and companionship comes from being together in my house, their family home. The love for them is the same. I cried for hours the first day, torn between wanting to protect my family and the devastation of being torn apart. Knowing my family would need additional mental health support, income for essentials and something to occupy their time, I pulled myself together.

My family are incredibly capable and intelligent, but their mental health difficulties cause them such anguish. The effect of these conditions is like a toxic tar. Sometimes it is beaten back until the tar trickles off like rain; other times it is thick, dark, sticking to their legs and emotions, making each footstep in life unbearable. I raised them on the principle we can face anything together, guiding them through the pain of their pasts. They make me proud every day, taking life by the horns, inspiring me.

It is equally important that my children have space to retreat when overwhelmed by their conditions as it is to have space to receive care, companionship and manage medication intake. Their conditions increase the risk of self-harm and suicide. It was, and remains, vital they could come to my own home, where I could discreetly check their arms for cuts and provide support. In times of crisis, before they completed any acts of self-destruction, they would come home where they were supported, and we got through their crisis together. Mental health services rarely return their calls the same day, leaving the onus of care on me. However, restrictions prevented me from providing this essential care when needed.

Pre-lockdown, budgeting, medication and nutritional intake was managed and monitored. Impulsivity created further struggles with money management, and so we managed with whatever they had. I contributed anything additionally needed. Regularly, another family member turned up for dinner, having not eaten that day because of mental health issues or income. I often significantly reduced my portion to feed an additional one; it's what a parent does. Eating together was essential for routine, adding structure to our family and a time to look forward too, especially when conditions were too imposing for them to encourage themselves to eat.

A loan funded gaming subscriptions to play together as a family, and ensured each had money for food and essentials. Updated mobile phones enabled video-calls to provide supportive care and encouragement. It was essential I continued providing necessary care for their mental health, but these methods did not provide a suitable alternative to pre-lockdown support.

At the beginning of lockdown, my children were angry, feeling imprisoned in their homes. I listened, trying to ease intense emotions of abandonment and suppression, emphasising the

*Pseudonym names used for confidentiality

rules were there to protect us all, explaining government reasoning. Allowing them to release pent-up emotion helped them, but I couldn't escape my feelings of guilt and helplessness. They needed me to keep their spirits up, but we couldn't be together. The isolation just increased their symptoms, leaving me constantly worried as each day they got worse.

Throughout lockdown, Luke* talked of suicide and life being worthless. Everything they loved and needed was taken away. Through listening, comforting and empathising, I became a target to externalise emotions, believing this was better than internalising the feelings. Panic rose in me daily, each morning checking for active online status, proof that they had made it through another night. Conversations became unbearable for Luke; he regularly replied 'Leave me alone'. I worried the time on their own had become a miserable self-prison to which they had become accustomed. Disengagement made monitoring medication intake impossible.

Through their misery and anxiety of lockdown, hopes of their willingness to talk were often unrewarded, and video-calls meant I could no longer discreetly monitor for self-harming. Contact methods available provided insufficient communication and support to Luke. Lockdown meant Max lost his job, going from having a purpose to nothing. Initially, he remained optimistic about finding another job. I was incredibly proud but, over time, he, like many others, was applying for every job with no success. Each video-call showed his deterioration, becoming withdrawn, pale and miserable and not doing his hair. No matter what I said or tried, he told me "life was pointless", spoke of suicide and how alone he was.

Knowing my children had previously attempted suicide, lockdown caused a constant state of worry. I was drowning in duty and need, bouncing from one form of contact to the next; worry for my children stopped me sleeping. Four months into restrictions, the situation had triggered depression and anxiety in myself, further reinforced by my mother becoming terminally ill. Restrictions meant I couldn't support her either. Addressing my depression and anxiety with my GP, I regained control of my emotions and continued doing my best, caring for my informal family, however I could.

* Pseudonyms used throughout

Commentary from Chartered Psychologist Pooja Saini:

Across the UK, local restrictions are robustly enforced to help prevent the spread of Covid-19. These precautions aim to prevent the spread of infection (British Medical Association, 2020). However, the isolation of local lockdown inevitably has a negative impact on some people's mental health (Usher et al., 2020). The government allowed for separated traditional parent households, enabling care for young children or exclusive bubbles for single-person households. However, as the UK is more diverse than the outdated view of a "typical family and their needs", these criteria do not meet all families' needs. Informal families, such as informal fostering or caring, have been neglected and forcibly separated.

The Department of Health and Social Care (DHSC; 2016) defines informal/unpaid carers as: 'people who look after family members, friends, neighbours or others because of long-term physical or mental ill-health or disability, or care needs related to old age'. This does not include any activities as paid employment. That person may be within or outside of their household, and might be sick, disabled or elderly themselves. In 2018/19 approximately 7% of the UK population were providing unpaid care and it was estimated that 1.4 million people were providing 50+ carer hours a week for a partner, friend or family member in the UK (DWP, 2020). As such, they make a significant contribution to society and the NHS (Buckner & Yeadle, 2016; NHS England, 2015).

The NHS acknowledges this contribution, saying it was 'critical and underappreciated not only to loved ones, neighbours and friends, but to the very sustainability of the NHS in England' (Carers UK, 2020). Many informal carers are providing support to individuals at risk of suicide. Prior to the pandemic in 2019, male and female suicide rates in England and Wales were at an all-time high (ONS, 2020). Male suicide rates increased from 15.5 deaths per 100,000 in 2017 (ONS, 2018) to 16.9 deaths per 100,000 in 2019 (Lacobucci, 2020). Longer waiting lists and less support from the NHS leaves the expectation to care for mentally ill individuals on family, friends and the individual themselves, potentially increasing suicide risk.

Aside from the economic and social cost of suicide (estimated at £1.7 million for one suicide: Knapp, McDaid & Parsonage, 2011), the impact can ripple out from the individual: Cerel et al. (2018) argue that around 135 people are directly affected by one suicide. Thus, in the UK, 878,445 people may have been affected by suicide in 2018, and we should go beyond a focus on kin or those who were exposed to the trauma of the death itself, instead defining individuals exposed to suicide as *"anyone who knows or identifies with someone who dies by suicide"* (Cerel et al., 2014, p.4).

A multi-faceted approach with multiple interventions is needed to support individuals in non-traditional families, to ensure that all needs are considered, not just the risk of Covid-19 transmission. When an attachment figure supports the need for proximity and reliably responds quickly to the need for support, this, in turn, provides a secure space for the individual to feel supported and optimistic regarding the attachment. This aids emotional regulation (Shaver et al., 2016) and has reduces stress responses (Karremans et al., 2011). However, when the attachment figure is absent, emotional regulation becomes more difficult and feelings of worthlessness, abandonment and reduced self-efficacy surface.

We can also consider Sam's situation in terms of the Transaction Model of Stress and Coping (TMOSAC; Lazarus & Folkman, 1984) where stress is an interaction/transaction between the environment and the individual. Once a stressor event is encountered, a primary appraisal takes place. If the individual classes the event as harmful or stressful, according to TMOSAC, an individual will then make a second appraisal regarding whether they have sufficient resources (such as emotional and social-support or finances) to cope with the demands. In Sam's case, insufficient resources/abilities to meet the demand inevitably leads to stress.

If informal carers are no longer able to provide essential mental health care and social support, who will? What happens next? The carers will suffer, the vulnerable adults they care for will suffer and the NHS will suffer as a direct result of restrictions.

We make the following recommendations:

- Larger support bubbles for single vulnerable adults, including a registry system to remove anxiety of being stopped by police.

- Financial aid to prevent digital poverty, enabling vulnerable adults to connect to their support unit, perhaps take an online course or use the internet to provide access to wellbeing services and time-consuming activities or media (just as laptops etc. were provided to children in education).

- Increased and more immediate access to mental health crisis teams during the pandemic.

*Pseudonym names used for confidentiality

- Peter Blaney, is an Undergraduate psychology student at Liverpool John Moore's University.

- Pooja Saini, FHEA, CPsychol, PhD, MSc, BSc, is a Senior Lecturer in Psychology at Liverpool John Moore's University, and Lead Researcher at James Place Therapeutic Service for Men. P.Saini@ljmu.ac.uk

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