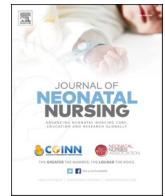


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The humbled pivoting voyeur and the shelved and boxed grieving parent - a story of real-time qualitative research in the COVID-19 pandemic

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ABSTRACT

This reflexive piece uniquely discusses the challenges faced by a researcher (PhD Student) conducting real-time longitudinal research during the COVID-19 pandemic. It draws on data gathered from the author's reflexive diary and participant transcripts from an interpretative phenomenological analysis (IPA) study utilising online diaries and semi-structured interviews. Participants were asked about their experiences of shielding their children, who were born preterm, during the COVID-19 pandemic. The note, reflectively and transparently, describes the research experience from the perspective of the PhD student. It explores the complex relationship formed between the researcher and participant, and the impact of this relationship throughout the research process. The piece highlights unforeseen and unintended psychological consequences of research during a global pandemic.

... I'm very very tearful. ... Erm because I've got the- ... it's- it's always the bereavement sort of- it runs along in the background it's always there I would say it's like a- ((Eddie vocalising)) one of those computer programmes that's always on, it's a tab that's always open in my mind ... so I tend to have a good cry ... erm ... ((sigh)) one of my best coping mechanisms, is just to talk to my husband, coz he's brilliant. Alexandra, Interview 462-470

I have written this piece amid a daily grapple with data analysis. Analysis that I have actively avoided. I've shelved it, and then barricaded the shelves with another bookcase. The data analysis affects my mood, and fills me with a combination of regret, dread, and pride for embarking on such a study. Like most people I found lockdown difficult. A closed family business, "home-schooling" a somewhat reluctant 3-year-old, and a 6-year-old who is a bilateral hearing aid wearer. Born preterm at 27 weeks, she has a myriad of mild long-term impacts of prematurity, some of which we are still discovering. What I soon learned was that hearing aids can be challenging for zoom learning, and so days of her wailing, visible to other families, increased my stress levels considerably.

As with my own experience, literature discusses the unequal gender-specific burden the pandemic placed on women in academia, managing both work roles and home-life (Akyildiz and Durna, 2021; Gewin, 2020; Rode et al., 2022). Additionally, PhD students and the wider academic community were faced with detrimental impact to their psychological and social wellbeing (Abdellatif and Gatto, 2020; Beatson et al., 2021; Börgeson et al., 2021; Khan, 2021; Paucsik et al., 2022; Rodrigues et al., 2021).

During this time, I pivoted my PhD and opted to re-design and adapt studies in hope of continuing my completion trajectory during a pandemic with an indefinite end point. Short essays reflexively discussing the PhD-pandemic experience confirm I was not alone in facing the dilemma of adaptation or awaiting a return to the field (Tulumello and Favilla, 2020). Schwarz and Stensaker (2020) highlight the rare opportunity that the COVID-19 pandemic created to produce real-time research of a multifaceted phenomenon; however, the word pivot perhaps does not give justice to the personal upheaval I experienced by doing so. The word suggests gracefully oiled turning with ease. I should have perhaps described it better as taking a bulldozer to the expertly laid dry-stone wall that was my prior thesis plan.

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Several manuscripts acknowledge the difficulties in personal lives faced by academics whilst presented with research opportunities and challenges to staff roles and research (Akyildiz and Durna, 2021; Börgeson et al., 2021; Bratan et al., 2021; Hlongwa, 2020; Khan, 2021; Pyhältö et al., 2022; Rodrigues et al., 2021; Schwarz and Stensaker, 2020). PhD students and academics were confronted with interrupted research activities, funding, extended study duration with associated fees, delays to anticipated academic career trajectories and reduced opportunities to network and engage in academic collaborations (Hlongwa, 2020). Studies found further detrimental impact on engagement in academic work (Beatson et al., 2021; Paucsik et al., 2022), research timetables (Beatson et al., 2021), supervision (Börgeson et al., 2021), limited access to data and affected access to resources (Pyhältö et al., 2022).

Crucially, Börgeson et al. (2021) identifies PhD students as being a “vulnerable group” due to financial and time demands impacted by delays associated with COVID-19, despite free of charge PhD programmes in Sweden, acknowledging the increased vulnerability PhD students would experience in other countries.

Despite these barriers, Haas et al. (2022) conducted a career survey of 329 PhD students in the United States of America prior to and following the pandemic, and found that COVID-19 did not impact the academic ambitions and priorities of PhD students as hypothesised. Aydemir and Ulusu (2020) expressed in a commentary in the journal of Biochemistry and Molecular Biology that an opportunity should be seized in the pandemic to engage with literature, study design, data analysis and writing manuscripts rather than suspending career progression. I also felt suspension was not a viable option.

My opportunity to work was between 5am and 7am and from 6pm to the point I fell asleep. I spent my evenings downloading COVID-19 related journal articles, trawling databases which returned hundreds of results daily, with many articles of poor quality. To expedite knowledge sharing at a critical time, the pandemic led to a substantial increase in pre-print research (Gewin, 2020). This research was made publicly available prior to peer review to facilitate quick dissemination of information relating to COVID-19. However, this led to the potential for publicised poor quality research (Dobler, 2020; Iida, 2021), with further challenges faced when conducting systematic reviews including overburdened peer reviewers and a continuously evolving pandemic landscape (Iida, 2021). Despite the research opportunities that COVID-19 presented, Rodrigues et al. (2021) acknowledges the challenge that all fields lacked an existing evidence base, understanding and experience of the pandemic. This global inexperience both increased feelings of professional isolation and added to the personal isolation experienced in the pandemic.

I declined invitations to online quizzes with friends, video-calling, and any element of personal reprieve to further my noble crusade of keeping up with COVID-19 research. Research that told of deaths, optimistic potential treatments, and of the grave psychological consequences of a global pandemic.

An editorial by Velho (2020) likens the experience of enforced isolation due to the pandemic to enforced isolation during the PhD programme due to the autonomous nature of PhD research completion. Velho (2020) questions “Why do we perceive enforced isolation as monstrous in times of the pandemic, but a requirement during the PhD?”, indicating the need for the evolution of the doctoral training model to address the negative mental health consequences that PhD students experience. The isolation I experienced was two-fold; mandated pandemic-related isolation and autonomous study in a novel, emerging field.

And then my main study began. I designed a study to understand the experiences of parents who were shielding children who had been born preterm. It utilised an interpretative phenomenological analysis (IPA) method (Smith and Nizza, 2021), and asked participants to document their daily experiences in an online diary, followed by an interview once shielding ended. Several studies utilised the use of diaries as a real-time

qualitative data collection method during the COVID-19 pandemic (Kerman et al., 2021; Saltzman et al., 2021; Scott et al., 2021; Shao et al., 2021; Sun et al., 2021; Vowels et al., 2021). Romani et al. (2021) used diaries as a real-time data collection method and highlighted benefits of the naturalistic context and a reduction in the probability of retrospection.

I was struck by the depth in which my participants engaged. The outpouring of rich, personal, data. I have come to understand that richness is what many IPA researchers dream of obtaining. Rich, emotive data peppered with metaphors and complex linguistic choreography. Diaries have been frequently used as data collection methods in IPA (Boserman, 2009; Cameron, 2016; Humphrey and Lewis, 2008; Maxwell et al., 2011; Montgomery et al., 2009; Smith, 1999).

Each day I nervously logged in to see if participants had submitted entries, and as I read them, I felt like a voyeur. A sinister one-sided *peeping Tom*. It gave a window into their lives in real time. Some days I was eager to read entries and some days I was hesitant. Some entries eloquently expressed the lack of support from friends and family, the health service, and educational authorities. And there I was, soaking in these experiences and doing absolutely nothing to remedy their atrocious circumstance. An editorial by Velho (2020) acknowledges that despite personal occupational characteristics and resilience, witnessing the human loss in the pandemic has an unavoidable impact. I agree.

Participant five touched me. We shall call her Alexandra. I saw myself in her. She provided me with a new lens in which to view the world and to understand the current turmoil of the pandemic. We had some shared characteristics, Alexandra and I. I was in awe of her. Alexandra is the mother of a surviving twin. She was charismatic in her writing, resilient, generous with her innermost thoughts, insightful into her own psychological processes, funny ... and at the same time, wading through the unimaginable grief of losing a child. Her diary entry illustrated this:

We haven't looked at Robson for almost a year now. ... The photos of him when he had died were more gruesome than I remember. I always said that he had died a long time before they eventually brought him to us and took out the breathing tube. ... We weren't just watching him die. It was all over a long time before. So, today, I wonder whether the almond milk really was off. Or did three hours of twisting pain and hot water bottles and paracetamol come from somewhere else. (Diary Entry 3 27/05/2020)

I felt as though I watched Alexandra stumble through the cycle of grief with grace as her diary entries were submitted. A silent listening ear. Her entries provided gut-wrenching emotion and an insight into grief that textbooks trivialise into a single infographic. An unintended, unplanned outcome of the research. I felt woefully unprepared and simultaneously grateful.

It was Robson and Eddie's birthday yesterday, I told [*my husband] that I couldn't celebrate a 'birth-day' because it was an awful day, but I could celebrate Eddie still being here. (Diary Entry 5 (31/05/2020)

Her grief was impeded by the pandemic. She recognised that. The anger and frustration she felt by those so physically close to her was palpable, who she witnessed experiencing having a different version of pregnancy and a different version of the pandemic. She felt unheard:

Next door ... the people in the front garden are having a baby. She is pregnant. I want to tell her my baby died. They don't know my baby died. But I want to tell her. I want her to know there is risk in the world. Not all pregnancies are simple, lovely things, with normal outcome. Her baby will be fine. It will be born at the right time, and it will come home. (Diary Entry 1 22/05/2020)

I felt guilty. I had spoken to someone on the doorstep. Would I have been someone she would be frustrated by? As a parent of a child that was born preterm and as a researcher leading this topic, I felt dishonest or

hypocritical for living as a non-shielding family. [Enosh and Ben-Ari \(2016\)](#) (p.578) define reflexivity as “the constant movement between being in the phenomenon and stepping outside of it”, occurring in the liminal space between both the inside and outside, by a process of discovery and construction. During the analysis I was never static. Like the definition, my position as a researcher felt fleeting and rarely grounded.

The shift in insider-outsider status was also noted by [Hill and Dao \(2021\)](#) who initially believed themselves to be insiders but found identification as an insider/outsider to be “fluid” (p.522), directed by participants. Hill entered the research setting recognising personal past similarities to participants (experiencing poverty) but acknowledging that her present circumstances were no longer experienced. This captured my personal quandary. The literature led me to re-question my self-proclaimed insider status. Do we have the right to self-identify or does the participant ultimately make that decision?

Furthermore, I resented the impact of what the PhD process had inflicted upon her. Social media is often awash with memes and content that can cause unintended pain. She stumbled across a tweet on Twitter of a student who had submitted their thesis:

... called herself 'mother' and the PhD 'baby'. She said the 'baby' had been 'safely delivered'. I wanted to type in block capitals "A PHD IS NOT BABY". ... Babies are not always safely delivered. Some deliveries are full of terror and crushing loss. No delightful post-partum photo with baby on chest. No smiling parents gazing at child. No phone calls to all and sundry cheerfully announcing the birth. (Diary Entry 4 29/05/2020)

[Borgstrom and Ellis \(2020\)](#) (p.4) define reflexivity as “an explicit self-analysis of one’s own role in research”. I wondered how many times we researchers make mistakes. I, as a researcher, had entered a tangled symbiotic relationship between the research itself, the researched. Her writing was vivid and evoked pain in me. Pain at a time that I was already experiencing my own pain of a pandemic and memories of my own neonatal intensive care (NICU) stay with my daughter. Lesser pain. Had I ever experienced pain like Alexandra? No. I had not experienced loss. And then came the crushing guilt and shame.

I contemplated my simultaneous insideness (experience of a pandemic and being the parent of a preterm infant) and outsideness (I was not shielding and had not experienced child loss). Like having one foot over the threshold of the door. [Gair \(2012\)](#) (p.137) understands insider/outsider research positions as “the degree to which a researcher is located either within or outside a group being researched, because of her or his common lived experience or status as a member of that group”. Was I inside or was I outside?

How could I feel like I was struggling in a pandemic when Alexandra was dealing with such challenges with courage? How could I have struggled so much with a NICU stay with my daughter when I walked out of the unit with her in her car seat, months after her birth? I leaned heavily on what became a 30,000-word reflexive diary of data collection as my own outlet. Although the diary was implemented to mitigate the criticism of a lack of objectivity within insider research ([Brannick and Coghlan, 2007](#)), it proved invaluable. Perhaps the reflexive diary mirrored the creative outlet that my research provided for Alexandra.

[Abdellatif and Gatto \(2020\)](#) reflected, through a feminist lens, on the experience of being both a PhD student and parent in the time of the COVID-19 pandemic in the United Kingdom. Abdellatif acknowledged the personal challenge of the pandemic whilst having an awareness of positionality in relation to others experiencing domestic abuse, loss of employment and those experiencing loss of children and family members. Both authors reflected on personal privileges, mirroring my own thoughts that filled the pages of my reflexive diary.

As a registered therapist I know that such comparisons are at best rarely helpful, and at worst damaging. I also know that we should accept our thoughts and feelings. I then felt repeated crushing guilt and shame that I was again, considering my own feelings at a time when Alexandra and her fellow participants were fearful of the lives of their children.

Gatto reflected that studying felt “self-indulgent” (p.729) in comparison to his wife, working in the National Health Service ([Abdellatif and Gatto, 2020](#)). Self-indulgent. Perhaps this piece is too.

Alexandra was someone who I felt would be a friend in real life and yet was pouring out words of isolation and grief. I wanted to reach out to her, through the computer screen, and for her to know that I was there and that I truly heard her. I saw her. Research ethics and processes do not permit such human engagement. Would it truly taint the study to let her know I was listening? Reflexivity, along with ethical mindfulness is vital when considering research dilemmas with an ethical component and enrich each other ([Bowtell et al., 2013](#)). [Brannick and Coghlan \(2007\)](#) acknowledge the role duality that insider researchers may experience, touching upon role confusion and value conflict. Conflict summarises my experience. On days where she didn’t submit an entry, she often crept into my thoughts. I want the world to know her story and be as touched by her as I was.

Physical harms can be more easily identifiable, yet qualitative research acknowledges the significance of interpersonal connection ([Bowtell et al., 2013](#)). When I interviewed Alexandra, I was nervous. I held her on a pedestal, in such esteem as the fictional “Wonder Woman”. I wanted her to approve of me, the person who would tell her story to the world. Would she find the questions trivial? Would she trust that I would do the memory of her son justice? When reading her diary entries, I could mentally compartmentalise Alexandra, like a fictional character in a novel. The interview was when that character became real.

She expressed as openly in person as she did in text:

... always was top to tail so ... and then they were suddenly quite violently ... drawn apart and never put back together again. ... So I often feel is he- is he lonely? ... does he ... terrible what you think isn't it? Is he lonely? Does he know that he's missing something? And, is he missing ... half of him? Which I know is- is really like ... so, lyrical isn't it to say oh he's missing half of him but he kind of is ... Erm, and he doesn't have any he's had no other contact with other people ... apart from medical professionals ... that's all he's ever known. And the only, contact he had during the shielding period ... was with, erm, the lovely nurses at our GP's [General Practitioner] practise who, put an injection in every arm and every leg. ... So ... so that's his re- I was thinking, have I traumatised him by showing him that other adults, will hurt him? (Interview, 09/07/2020)

I am not ashamed to admit that I shed tears when transcribing her interview. As that transcript ended, I realised the research-participant relationship was over. I felt the emptiness of loss. I wanted to know how her story resolved and how she navigated her re-entry into a post-pandemic world. [Hanna \(2019\)](#) studied researcher emotion with one of the themes being “what happened next?”, discussing that researchers may feel a lack of closure, concern and worry for the outcome of the participant. Other participants were equally experiencing and expressing intense feelings, so much so I had to escalate safeguarding concerns. I wondered what was so different about Alexandra? Why is Alexandra so hard to analyse if I felt connected to her the most?

[Borgstrom and Ellis \(2020\)](#) draw upon their prior ethnographic fieldwork and query whether the introspection that comes from reflexive practice can be considered harmful, specifically for death researchers. The research evoked personal vulnerabilities and recollections of my own experiences.

Perhaps it was because that connection was mutual. Alexandra directly spoke to me. She made a connection with me as a researcher. She used words suggesting direct communication, for example, apologising to me in her entry:

Sorry it's been so long. I think I'm struggling a little. (Diary Entry 10 18/06/2020)

The desire to make a connection was one of the most poignant moments in the research process. [Ross \(2017\)](#) described benefits to the

researcher including feeling comfort, reassurance, validation, and a new way of thinking. Conversely challenges included emotional triggering and negotiating relationships. This account touches upon each of these benefits and challenges.

She told me of the therapeutic benefit of completing the diary entries, and her reluctance to end them. Like Alexandra, research reports the cathartic and reflective experience of participants who have engaged in phenomenological research using diaries (Mole et al., 2021; Morrell-Scott, 2018). She felt something in this process too. The quote that summarises her experience of the pandemic is:

We have been ‘away’ for so long. And I think that helps people. I think they can put us in a box and not think about it (because who would want to?) and maybe think it has all gone away and time has healed. But time will never heal the death of a baby. ... And lockdown has added on to the ‘in the box’ time. And people are getting on with their lives and not thinking of us. And I have to try to accept that. (Diary Entry 4 29/05/2020)

Nobody should feel shelved like an object in a box. Is that what I inadvertently did to her too? Was analysing the data too difficult, selfishly too challenging, and I too shelved her?

After writing this piece I feel able to re-open Alexandra’s transcripts and finally complete the story. I suspect that I will carry her words for many years. That they will hauntingly continue to linger in my mind. I hope that all qualitative researchers have the privilege of a participant like Alexandra. A participant that teaches you about yourself and reminds you of what a gift it is to be a researcher. Despite that finality, I was left pondering the question of conditionality raised by Oakley (2016) as to the understanding that the participant enters research knowingly, relinquishing power and control over the research output. Despite the concluded notion of Oakley (2016) that the gift is not conditional upon receipt, I negotiated the content and form of this piece with Alexandra. So perhaps the scales of power balance moved centrally and our relationship of researcher and researched was indeed reciprocal. Despite my guilt and initial feelings of voyeuristic inadequacy, perhaps we did give each other a gift during a time of isolation and uncertainty. That tentative conclusion can only be known by Alexandra. We are all left without closure.

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Author’s contributions

KC produced this manuscript. DH, JR and AA contributed to the editing of this submitted manuscript. All authors read and approved the final manuscript.

Declaration of competing interest

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