



UWL REPOSITORY

repository.uwl.ac.uk

A journey through reproductive loss and autoethnography: The importance of a guide through the uncharted territory.

Lafarge, Caroline ORCID logo ORCID: <https://orcid.org/0000-0003-2148-078X> and Douglas, Kitrina (2024) A journey through reproductive loss and autoethnography: The importance of a guide through the uncharted territory. *Journal of Autoethnography*. (In Press)

This is the Accepted Version of the final output.

UWL repository link: <https://repository.uwl.ac.uk/id/eprint/12080/>

Alternative formats: If you require this document in an alternative format, please contact: open.research@uwl.ac.uk

Copyright: Creative Commons: Attribution 4.0

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy: If you believe that this document breaches copyright, please contact us at open.research@uwl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Rights Retention Statement:

A journey through reproductive loss and autoethnography: The importance of a guide through the uncharted territory.

Caroline Lafarge, Kitrina Douglas

Caroline Lafarge is Professor of Psychology and Head of the Graduate School at the University of West London. Her research focuses on health psychology, particularly reproductive health and health interventions. Specifically, Caroline's research centres on experiences of prenatal diagnosis, decision-making and healthcare during the perinatal period, as well as of pregnancy termination for medical reasons.

Kitrina Douglas is Professor of Narrative and Performative Research at the University of West London. She is an award-winning researcher whose work spans the arts, humanities and social sciences. Kitrina has developed a passion for making research accessible to lay and public audiences, and to work in ways that challenge stigma and discrimination - especially in areas surrounding mental health and illness. As such her work is published as films, documentaries, poems, songs, stories and musical theatre, along with written publications in traditional academic peer reviewed journals and news media.

Keyword: reproductive loss, abortion, collaborative autoethnography, poetry, pedagogy

Abstract

Over the many years I (Caroline) have taught reproductive health and conducted research in the area of perinatal loss, I have written and spoken about the strength, courage and spirit many individuals display when facing such experiences. But I have also become increasingly aware that I would have to, at some point, revisit my own experience of perinatal loss and understand how it fits within the research I have conducted, the individuals I have befriended over the years and my own development. Today is my first step in my autoethnographic journey. It is also my first attempt at reconciling these different aspects of my experience, and in doing so at moving to a different way of grieving the loss of my babies, and particularly the loss of my son.

It has taken me 16 years.

Overture

There is no I

We are formed in dialogue

Without the other, without dialogue, there is no one to tell the story to

Without the other, there is no one to invite the story

We are reminded of Arthur Frank "stories can be told when they can be heard"

Kitrina: I am listening

Tell your story

Background

I came to autoethnography late in my academic career. Within the Psychology courses of my student days, autoethnography was not only not taught but it was not acknowledged as a valid research method. To this day, at the university where I work and carry out research, autoethnography is not on the Psychology curriculum. More recently, however, I have starting hearing respected colleagues, such as Kitrina Douglasⁱ, present their autoethnographic work. I have found this work fascinating, but it was hearing them speak about their experience of producing autoethnographic work that particularly interested me. Being exposed to the idea of being able to dig deep into self-reflection, of authorising oneself to be seen – not just as an academic but as a human being - and being part of a supportive community, or at least the possibility of this, really stroke a cord with me.

To me, autoethnography represented experiential work unlike anything I had ever contemplated doing before. It was intriguing, daunting and puzzling but it also coincided with a time in my life where I was more open to the idea of self-reflection, and when perhaps I needed to revisit my own experience of perinatal loss, in particular terminating my second pregnancy at 28 weeks' gestation due to my baby's brain abnormalities.

Pregnancy termination for fetal abnormality is, unfortunately, not an isolated experience. In England and Wales, it is more common than stillbirth and its prevalence has been rising over the past 15 yearsⁱⁱ. Yet, it is seldom spoken about and remains a form of bereavement that is misunderstood and stigma bearingⁱⁱⁱ.

For the past 16 years, I have been researching this topic^{iv} as well as perinatal experiences more generally^v. Reflecting on these events and being introduced to a way of including my experiences rather than distancing my emotions from the topic, provided me with the tools to start integrating my story to the work I had been doing. It simply "felt right" to "begin" this work.

Staying or living with my story over a prolonged period of time has been an uncomfortable experience. For the past 16 years, although never forgotten, my experience had been delicately put in its box, with a nice, clear label on it [Tadzio] and placed at the forefront of my memory. But that was it: it was a cherished box of archives full of mementoes, poems, letters from loved ones, but also ultrasound images and hospital letters. Writing about it in different ways allowed it to break free and have life breathed into

it - a little bit like a benevolent genie. And I could observe it, unable to control it, but intrigued as to what it would do and where it would go. This was my 'genie' moment.

In what follows I present my experience in poetic form through four moments. I will then offer some reflections on some of the factors that made this research possible.

Title of the poems

For Tadzio

1. Beating hearts

first pregnancy

I'm afraid there's no heartbeat

Says the sonographer,

But

I was

carrying twins

two heart beats

missing

and mine

three heart beats

a trio

in harmony

my heart misses a beat

no wait, two beats

miscarriage at 11 weeks

but it's not that easy,

the body refuses to give up

Frozen, it holds on,

I hold on

Until the pain overcomes

Back in hospital

Again

Could not sign

the consent form

It felt like

signing my life away

It was all down to me

And only me

Long, protracted decision

An alien world,

A different language

So far from home

Yet at home

Nature refusing to take its course

Vacuating my inside

I failed

at sustaining life

at letting go naturally

I am scared

Scared for myself

Scared of going under

Of the darkness

Of what's to come

2. Shattered world

I felt I had recovered well,

I had my first child

A little girl aged 3

Pregnant again,
Only one heartbeat this time,
I was happy

Today we are going
To find out the sex
Joy, trepidation, anticipation
“It’s a boy”!
the sonographer says
Wandering mind
Baby boy,
first steps,
boy clothes,
haircuts,
school bag
scooters,
first fall
first cut
growth spur
Teenage boy
Adam apple
Young man
Father

And then, silence
Long silence
“Something with the brain”
She said
Ambivalence
Hope and despair

3. Limbo

8 weeks of nightmare

Blood tests, scans and noisy MRIs

Embodied emotions

Hormones

Adrenaline, Cortisol

Shaping his brain

Oscillation

Getting better, getting worse

Trying to keep up

With the natural growth

of our baby's brain

Ambivalence

Attachment and detachment

Wanting more time

Wanting less time

Time with him

Time in hope

Time running out

Decision to make

A Sophie's choice

But not before

I could make sense

In my own language,

So I could REALLY KNOW

"C'est pas beau du tout",

said the French consultant

Of what he saw on screen

And so, the decision is made
To terminate the life
of our baby boy
Before he was born
I stopped his Heartbeat
Because I loved him

4. Guardian

I felt so tired
Heavy, sluggish, empty
I felt relief too
To no longer suffer
At least
Not in the same way
Different sufferings

Longing
For the weight of him in my tummy
Loss
Of him
Of potential
Of innocence

Anger
At us, his parents
For not wanting him enough
At others
For having living babies

Oscillation
Between grief and restoration
And such a lonely place to be

Keeping the balance
Guardian of his memory
Guardian of the family
Saying enough
But not too much
Not projecting
Not transferring
Onto a new pregnancy
Onto another child

But somehow
A delicate, durable shift
New directions
Self-discovery
Connection to others
Sense of purpose
Yet, always with me
Part of me
Never forgotten
Especially you
Tadzio

Reflections on pedagogy

Producing autoethnographic work was totally alien to me. To be blunt, I did not know whether I was capable of it. That is, of writing in the first person, of weaving myself into a text, or allowing my emotions to take centre stage. Initially when I began this work, my conscious brain took over, and I began writing and presenting an argument as I had been schooled to do within the psychological sciences; narrating the facts, observing them without being in them, and reporting them in a chronological distanced report.

Having witnessed what an autoethnography might 'look like' and being a witness to the power of a performance, there were a number of factors that helped me begin the process of writing more emotionally and compassionately^{vi}.

Encouragement

It is only through encouragement from trusted friends – in particular my friend and co-author Kitrina - that I tried different ways of expressing and writing about my experiences. I needed a push, a start, and Kitrina provided just that. From that point onwards, I found it relatively easy to write, beginning with a story, a chronological narrative of my experience. However, after Kitrina's suggestion, I moved into poetic form. I did wonder, at first, about writing poetry. This certainly was not something I was used to do - the last time probably being in secondary school. And so, panic and the spectre of impostor syndrome quickly rose within me. I had never considered myself capable of writing poetry. I was apprehensive about venturing so far out of my comfort zone; but the discussions as well as the attentive and nurturing guidance provided by Kitrina won me over. Together, we discussed the way poetry can tap into and convey painful experiences in ways narratives cannot^{vii} as well as the healing power that poetic autoethnography can hold^{viii}. But perhaps, the decisive factor in my writing a poem was that I had witnessed and experienced first-hand the power of poetry in the work of colleagues^{ix}. These pieces of work moved me in a unique and novel way, and thus, although a novice, I was prepared to explore.

And so, I started writing a poem and, to my surprise, it almost felt that the poem was writing itself. I no longer had to think about why I was prioritising parts of my experience over others, and how to justify that. This was extremely liberating, but with it came a copious dose of self-doubt. Was what I was writing remotely interesting? Was I able to convey the complexities of emotions and bodily sensations I remembered so vividly? Was I fair to the protagonists?

Having Kitrina's support through these iterations was invaluable. Without her encouragement, I would never have tried. While we are used to responding this way with students, it is less common among experienced academics. However, we had been talking about me producing a piece of autoethnography for some time, and it would regularly come back in our discussions. I found in her someone who could read my hesitancy and self-doubt, and who knew where I stood on the road to autoethnography. This was really

precious because I never felt pushed. Rather I felt like being waited upon with curiosity. I was a complete novice being guided by a wise individual.

As David Carless and Kitrina^x note with performances and song writing, gaining an early response to what I had written that was caring and sensitive, but also productive, was extremely helpful.

Public sharing

Secondly, having the opportunity to share this work publicly - through performing the poems - was essential. For example, I presented early drafts in very rough stages of being created at a department "Twilight" session at the university where we work. This was for a small group of a dozen colleagues and students.

The first time I read my poem, I did not know how I would feel. I read the piece – not very loud, I was told afterwards. Perhaps I was hiding a little bit behind the words, but the feedback was very supportive. Perhaps what touched me the most was the presence and feedback from one of my colleagues, who did not herself present anything but had recently shared with me her own difficult experience of bereavement. I felt that perhaps she was a little bit like me all those years ago, listening to people sharing their stories - sometimes very personal stories - but unable to share hers. I felt a strong connection with her and I felt heard by her. I may have projected my emotions onto her, but in that moment, her positive feedback – which felt a little bit like unconditional regard - did mean a lot to me. It also provided me with some confidence that the poems made sense and were meaningful to others, that they were worth sharing for the impact they had. Another colleague, a nurse practitioner, suggested that she learned a great deal regarding some of her patients who had resisted signing consent forms.

Another key moment in my journey was attending my first autoethnography conference. The conference was unlike anything I had seen or heard before. During the session where I read the poem, I could feel the supportive atmosphere in the room, and that felt very reassuring. But beyond this, I loved that academic rigour was still very part of the practice. Perhaps I had been scared to venture out of my comfort zone, but in reality, although the academic exercise itself was completely different, I was still very much within my comfort zone – it had just stretched a little bit. I had been scared of being intimidated, usually at conferences there is one person who seems to derive pleasure in interrogating

the presenter in a dismissive way. I have witnessed speakers being undermined and treated disrespectfully, and the threat and fear for many of us, mean we are silenced. However, at this autoethnography conference¹ people in the room simply seemed more attuned to experiential and emotional work, perhaps more enlightened - which is where I strive to be.

Having reflected on my experience of writing and performing these poems, it seems to me that it is essential for the novice autoethnographer to surround themselves with competent, wise and well-meaning individuals who can act as guides in what remains - for most of us, academics - uncharted territory^{xi}. Autoethnography can be emotionally risky but it is also extremely rewarding, not just for one's own self-understanding and growth, but also for the way it creates possibilities for empathy and connections with others. As for any new endeavour, it is important to identify a secure base one is encouraged to venture from.

Acknowledgements: This piece is dedicated to the babies I have lost, in particular, to my son Tadzio.

ⁱ Kitrina Douglas, "Signals and signs," *Qualitative inquiry* 18, no. 6 (2012): 525-532, <https://doi.org/10.1177/1077800412442812>; Kitrina Douglas and David Carless, "Gwithian Sands," LIVE from Gwithian under lockdown, May 6th, 2020. Film, 4 minutes 18 seconds, <https://www.youtube.com/watch?v=JS4hc4Ecjys>; Kitrina Douglas and David Carless, "The long run: A story about filmmaking as qualitative research," *Qualitative Inquiry* 26, no. 3-4 (2020): 281-290, <https://doi.org/10.1177/1077800418808549>.

ⁱⁱ Department of Health, 2022. *Abortion Statistics, England and Wales: 2021*. Accessed May 12, 2023, <https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2021>.

ⁱⁱⁱ Caroline Lafarge, Kathryn Mitchell, and Pauline Fox, "Termination of pregnancy for fetal abnormality: a meta-ethnography of women's experiences." *Reproductive health matters* 22, no. 44 (2014): 191-201, [https://doi.org/10.1016/S0968-8080\(14\)44799-2](https://doi.org/10.1016/S0968-8080(14)44799-2).

¹ International Conference of Autoethnography, 2023, https://www.youtube.com/watch?v=rfl62SzU_hE

^{iv} Caroline Lafarge, Kathryn Mitchell, and Pauline Fox, "Perinatal grief following a termination of pregnancy for foetal abnormality: the impact of coping strategies," *Prenatal diagnosis* 33, no. 12 (2013): 1173-1182, <https://doi.org/10.1002/pd.4218>; Caroline Lafarge, Kathryn Mitchell, and Pauline Fox. "Posttraumatic growth following pregnancy termination for fetal abnormality: the predictive role of coping strategies and perinatal grief," *Anxiety, Stress, & Coping* 30, no. 5 (2017): 536-550, <https://doi.org/10.1080/10615806.2016.1278433>; Caroline Lafarge, "Conducting research in a sensitive area," *New Vistas* 4, no. 2 (2018), <https://uwlpress.uwl.ac.uk/newvistas/article/id/69/>.

^v Caroline Lafarge, Gaëlle Larrieu, and Isabelle Ville. "Why do French women refuse to have Down's syndrome screening by maternal serum testing? A mixed methods study," *Midwifery* 110 (2022): 103351, <https://doi.org/10.1016/j.midw.2022.103351>; Caroline Lafarge, Sophia Rosman, and Isabelle Ville. "Prenatal diagnosis: Women's interactions with practitioners when severe abnormalities are discovered at birth," *Journal of Reproductive and Infant Psychology* 40, no. 2 (2022): 144-154, <https://doi.org/10.1080/02646838.2020.1812553>.

^{vi} Carolyn Ellis, "Compassionate research: Interviewing and storytelling from a relational ethics of care," in *The Routledge Handbook on Narrative and Life History*, eds. Ari Antikainen, Pat Sikes, and Molly Andrews (Routledge, 2016), 441-455.

^{vii} Andrew J. Garbisch, "Constructing identity by writing roots into life: a poetic-narrative autoethnography." *Journal of Poetry Therapy* 34, no. 1 (2021): 37-47, <https://doi.org/10.1080/08893675.2020.1846865>.

^{viii} David I. Hanauer, "Growing up in the unseen shadow of the kindertransport: A poetic-narrative autoethnography," *Qualitative Inquiry* 18, no. 10 (2012): 845-851, <https://doi.org/10.1177/1077800412456960>.

^{ix} David Carless and Kitrina Douglas, "Art-based research as waves of embodied engagement: Reflections on 'Across the Tamar'," *Journal of Applied Arts & Health* 8, no. 2 (2017): 241-253, https://doi.org/10.1386/jaah.8.2.241_1; Batsheva Guy, "I poems on abortion: women's experiences with terminating their pregnancies for medical

reasons," *Women's Reproductive Health* 5, no. 4 (2018): 262-276,
<https://doi.org/10.1080/23293691.2018.1523115>.

^x Kitrina Douglas and David Carless, "Finding a counter story at an inclusive, adapted, sport and adventurous training course for injured, sick, and wounded soldiers: Drawn in—drawn out," *Qualitative inquiry* 21, no. 5 (2015): 454-466,
<https://doi.org/10.1177/1077800414566687>.

^{xi} David Carless, "Where spirit meets bone: A meditation on embodied qualitative inquiry," *International Review of Qualitative Research* 16, no. 1 (2023): 33-38,
<https://doi.org/10.1177/19408447221114848>.