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Moving off Script: A/synchronous Storytelling with Family Carers and People with Learning Disabilities

Abstract

This paper is about digital storytelling in the context of health and social care research with people with learning disabilities and family carers in the United Kingdom. We explain how we were drawn to decolonial thinking in the formulation of 'metodologia otra' to think again about the processes and practices of (digital) storytelling in health and social care research. We conclude by reflecting on what we learned about digital storytelling methods and the need to 'move off script' as an ethical response to storytellers who want to tell the stories that matter to them in ways that matter to them.

Key messages:

1. Traditional research methods don't always allow people to participate about in research in ways that matter to them about things that matter to them
2. Digital storytelling has the potential to open up different ways of doing research
3. The principles of 'metodologia otra' are useful when thinking about doing research differently
4. The care people with learning disabilities give in caring relationships with family members is rarely recognised or recorded

Key words/short phrases:

care; caring; mental health; learning disabilities; metodologia otra; co-production

Can't Picture it. By Emily, a sibling of a person with a learning disability

[White background with black text being typed as author speaks]

I think of the future every day.

[Previous text backspaced; continues white background with black text being typed as author speaks]

Actually, more than that

Multiple times a day.

[Blurry image of white hands]

I worry

[Blurry image of white male with glasses looking away]

and I overthink,

[Blurry image of person sitting at desk with hands on laptop typing]

and ultimately I end up going over and over what the future looks like.

[Blurry image of ocean with individual sitting at shore]

Not only for my brother,

but my family, as his support network.

[Blurry image of two young individuals and two adults in field]

Nobody else will ever be an expert in him; like we are.

we are the four people in his life who know the very ins and outs of him as a person

[Blurry image of multiple rifles in a row]

like his triggers

[Blurry image indescribable]

Fears

[Blurry image of white male with blue hoodie covering his mouth]

behaviors

[Blurry image of person standing at end of hallway]

and actions.

[Blurry image houses in a row]

It's hard to think of him being cared for in a different setting other than our family home.

It's all I've ever known, and my family have known

[Blurry image of person holding a phone]

and I worry that no care provider will ever know him truly.

[Blurry image of ocean with individual sitting at shore]

I want him to live a full life, but I don't know how he will do that safely in the future.

[Blurry image of ocean with cruise ship]

The thing is I want my parents to have their lives back too.

[Blurry image of a white child with red hair on the left and white adult with blonde hair helping with something while gazing down]

And the only way that that is possible

[Blurry image of white hand on a white individual's shoulder]

is by letting go of my brother and allowing him to be looked after by local services.

[Blurry image of two people having a cup of coffee across from each other]

I think the future will always be uncertain

[Blurry image of white banner with an orange and blue pen]

as much as I try to plan. And structure things.

[Blurry image of an individual holding TV remote facing TV]

It's very much out of my control.

[Blurry image of two elderly individuals on a bench]

I worry about my parents getting older

[Blurry image of individuals on grass in front of ocean to the right of the image with one male on the left of two girls]

and the responsibility of my brother being down to one parent and my sister and I,

[Boy fades from image of individuals on grass in front of ocean to the right of the image with one male on the left of two girls]

or eventually just my sister and I

to be wholly responsible for someone as a person

[Blurry image of wooden rocking chair]

and take ownership of such big things like their health,

[Blurry image of someone holding orange bank card]

finances,

[Blurry image of people playing golf]

wellbeing

[Blurry image of two individuals around greenery]

and quality of life

[Blurry image of an individual walking in dark alleyway]

is a very scary concept.

[image fades out while soft sound of foot steps fades]

Introduction

Emily's story is about care, love, siblinghood and learning disability. It is also a story about worry and fear generated by inadequate support. Here we tell the story of how Emily's story, and other stories by family carers and people with learning disabilities, were created and what we learned in the process about caring relationships and about digital storytelling methods. The stories were generated as part of a research project working with family carers and people with learning disabilities called *Tired of spinning plates: an exploration of the mental health experiences of adults and/or older carers of adults with learning disabilities* (Award ID: NIHR135080).

This co-produced project explored the experiences of adult family carers of people with learning disabilities with a focus on mental health, care, services and support. We were particularly interested in how mental health and care are conceptualized as well as people's experience of the quality, accessibility and effectiveness of support. There has been an increasing recognition of the value of storytelling in health and social care research, however, fewer studies have focused on the experiences of family carers of adults with learning disabilities [Douglas et al., 2022].

In our story about storytelling, we describe how we 'moved off script' as we began to follow a different path in the research from the one we planned. As we tell this story, we explain how the work was shaped by the disciplines of critical disability studies (Goodley, 2017), Mad Studies (LeFrancois, 2013) and critical studies of care (Nishida, 2022), and how we were drawn to the decolonial formulation of 'metodologia otra' (methodology other) to make sense of digital storytelling practices (Harari and Pozzebon, 2024). We begin, however, by situating the stories in the socio-political context in which they were told.

Health and Social Care Systems and People with Learning Disabilities in the UK

The United Kingdom (UK), like many other countries across the globe, continues to experience a sustained period of austerity politics (O'Hara, 2024). Marginalised people have borne the brunt of the effects of cuts to public services and disabled people and family carers have not been spared the impacts (ibid.). Rather, in (post) COVID-19 pandemic times, disabled people and their families continue to be disproportionately negatively impacted by cuts to public services and support and experience wide ranging health and social inequalities as a result (Banks et al., 2024). The consequences of inequality are made visible in many ways, and the cumulative impact of health and social care inequalities can be seen in the mortality rates for people with learning disabilities in the UK. The latest figures available show the median age of death for people with learning disabilities is 62.9 years old (White et al., 2023). As we write the United Kingdom government is consulting on reforms which, if implemented, will see an additional

250,00 disabled people thrown into poverty (Joseph Rowntree Foundation, 2025). These reforms threaten disabled people's access to welfare benefits called Personal Independence Payments (PIP). PIP is intended to cover some of the additional costs of living with an impairment, but crucially it is also a gateway benefit to other forms of support for the disabled person and their informal carers.

As demands on family carers rise, the support available to them and to people with learning disabilities is reducing. In 2020, a study found that 40% of people with learning disabilities said that they had lost care and support as a result of social care funding cuts (NIHR, 2020).

A focus on siblings

We began with Emily's story about her family and so we wanted to provide a context for sibling stories, in particular, for this paper. Sibling relationships have often been the focus of social research (Edwards et. al, 2005; Punch, 2001), and, increasingly, the relationships between siblings that include a disabled sibling, are included within sibling studies. However, the focus of research is often on the (negative) impact of the disabled sibling on the 'adjustment' of the non-disabled sibling (Hayden et al., 2019). However, siblings have also told their own stories about their fraternal relationships. Jesse Ball's novel, *Census*, is inspired by his fraternal relationship with his brother, Abram which is re-storied as through a story about a father and son (Ball, 2018). Manni Coe writes about his relationship with his brother Reuben as they navigate a world that refuses to understand Reuben in (post) COVID-19 pandemic times. In research, the drawing together of sibling studies and critical disability studies has also allowed for the generation of counter narratives which emphasise the relational nature of care, support and the positive aspects of sibling relationships (Meltzer, 2018). And Davies (2021) challenges the speciesism and ableism of the Down syndrome-animality metanarrative reproduced in Doris Lessing's The Fifth Child (Lessing, 1988). Nonetheless, the dominant narrative in sibling research remains, and being 'the sibling of a disabled person' is often described as a 'risk factor' for poor mental health (Levante et al., 2023; Ryan, 2024).

Researchers have failed to engage with the messy complexity of care and support in families' lives and the socio-political context in which families experience care (Nishida, 2022). It is important to recognize that family carers' experiences of mental distress are deeply entwined at the intersections of disability and care, *and* poverty, gender and race and ethnicity (Goodley, 2014: Seedat et al. 2009).

In these deficit driven accounts, the relational nature of care is obscured and the care and support undertaken by people with learning disabilities themselves in caring relationships within their families and others goes unnoticed and undocumented (Runswick-Cole et al, under review; Ward, 2005; 2011; Runswick-Cole, 2024a,b; Smith et al., 2025). People with learning disabilities are storied as passive recipients of care, 'always the cared for and never the carer' (Ward, 2011:168). Relational models of care have troubled the binaries which position people as 'carer or 'cared-for' (Ward, 2011). And yet, when relational care is imagined as " a clean-cut reciprocal relationship" the requirement to 'give back" is deeply entangled with ableism (Nishida, 2022, 130). Nishida (2022: 145) suggests instead that we are all in 'messy dependency' with one another. Messy care is complex, fluid, multi-directional, rather than unilinear, and, crucially, messy dependency does not demand or assume mutuality or reciprocity. People with learning disabilities made stories about their messy care (Runswick-Cole et al., under review). Their accounts of caring for their friends and relatives, providing practical and emotional support for those around them are in stark contrast to the dominant narrative that deny people with learning disabilities access to the category of carer.

Theoretical perspectives: an intersectional approach

Our work is heavily influenced by critical disability studies (CDS). We draw from a critical disability studies perspective precisely because it values messy complexity and intersectionality (Goodley, 2017). By paying attention to the workings of neoliberalism, (post)colonialism, racism, (hetero) sexism and class, critical disability studies allows us to attend to the entanglements in the lives of family carers and of people with learning disabilities (ibid.). Crucially, critical disability studies understands disability as socially constructed through a system of norms which categorizes and values bodies and minds based using concepts of ability and disability (Schalk, 2017). CDS allows us to ask what disability can do to disrupt 'typical, common sense, normative human categories', including care and mental health and sibling relationships (Goodley and Runswick-Cole, 2016: 5).

Aligned with but separate from CDS is the field of Mad Studies (LeFrancois et al., 2013). In 2002, Peter Beresford, an academic and mental health service user, called for a consideration of how understandings of disability as socially constructed might also inform understandings of mental health. Beresford (2002: 282) suggested that a sociological approach could offer 'a different lexicon to mental health service users, based on ideas of support, personal assistance and non-medicalised provision'. In 2013, *Mad Matters: a critical reader in Canadian Mad Studies* (LeFrancois et al., 2013) was published and has since become a key text in the field. Just as disability studies challenges the dominant biomedical model of disability, Mad Studies rejects the medical model of mental health as 'a jumble of diagnostic prognostications based on subjective opinion masquerading as science' (Menzies et al., 2013: 2). Like CDS, Mad Studies is characterised as fundamentally 'interdisciplinary and multi-vocal' (Menzies et al, 2013, p. 10). Mad scholars and activists have played a key part in exposing the role of neoliberalism in the making of mad subjectivities (Menzies et al., 2013). They have revealed and challenged the workings of neoliberal-sanism which are understood as 'the systematic subjugation of people who receive a mental health diagnosis or treatment' (LeFrancois et al., 2013: 339).

More recently, CDS and Mad studies has also been brought into dialogue with studies of care (Nishida, 2022; Runswick-Cole et al., 2024b). Working at the intersections of CDS, Mad studies and studies of care, it is important to attend to a difficult history in which disabled people have been positioned as 'vulnerable' and as a 'burden' through conceptualisations of care (Morris, 2005). People with learning disabilities have been particularly marginalised in debates about care in which they are constructed as passive recipients of care and their care-giving is rarely recognised or recorded (Ward, 2011; 2015). And yet, as Ward (2011; 2015) argues, the binary of 'carer' and 'cared for' becomes much more blurred when care is conceptualised through the concepts of interdependence and relationality. In other words, we are all entangled in 'messy dependency' with one another (Nishida, 2022: 12).

CDS and Mad Studies connect with feminist and decolonial scholarship which has long emphasized the social, material and interpersonal contexts in which mental distress appears (Andermahr, 2015). And so as we started to tell the story of how we created digital stories, we were drawn to decolonial scholarship. 'Moving off script' in the digital storytelling workshops revealed the inadequacy of Western methodologies to capture the embodied knowledge and experiences of carers and the oppressive social care systems they faced, and drew us to the principles of metodologia otra (Harari and Pozzebon, 2024). Metodologia otra is framed by radical principles aimed at dismantling imperialist knowledge systems that devalue disability and care. These principles were forged through the critical world building work of Walter Mignolo, Paolo Freire and other decolonial scholars. We engage this work to generate new insights about digital storytelling as a decolonial method and to *include* and value the previously excluded knowledge of carers and people with learning disabilities (Harari and Pozzebon, 2024). Harari and Pozzebon (2024) articulate the principles as: 1) learning to unlearn; 2) *escrevivência*/writing-living 3) interculturality and 4) *corazonar/sentipensar* - thinking-feeling. We explore these principles to narrate the process of moving off script in digital story making below. However, next, we share the story of how and why we 'moved off script' in the digital storytelling workshops.

The Project: Digital Storytelling and Tired of Spinning Plates

We explored the mental health experiences of carers of adults with learning disabilities in co-production with people with learning disabilities and with family carers. At the start of the research, we convened the Tea and Cake public involvement group which comprised 4 people with learning disabilities and 6 family carers. They guided the project at each stage, shaping the design, delivery, analysis and dissemination of the research findings. The research took place over 7 phases: convening the Tea and Cake group (1); a rapid scoping review of the literature (2); co-design workshops, culminating in the generation of an online exhibition curating exhibits about carers' mental health (3); interviews with family carers (N=28) (4); digital storytelling workshops (N= 9 parent carers; 4 sibling carers) (5); analysis (6) and dissemination (7) (Smith et al; in press; Runswick-Cole et al., 2024 a.,b). This article focuses on learning to unlearn from the online digital storytelling workshops. Ethical approval was sought and granted from the University of Sheffield's Research Ethics Committee and from Queen's University General Research Ethics Board.

The workshops were facilitated by a team from the Re•Storying Autism project (Douglas et al., 2021) based in Canada led by Patty Douglas over the course of several months. The first workshop with parent carers ran over the course of four weeks, from October to November 2023, although for a number of parent carers, the completion of stories extended into 2024. Similarly, the second workshop with sibling carers was planned for four weeks beginning January 2024. We came into the second workshop series with the implicit expectation that sibling carers would be available and want to attend synchronous sessions; however, in the first session, when one participant appeared on the Zoom screen met by our team of five facilitators, we realized a different approach may be required.

As we began the storytelling phase, we set out with a plan modelled on other online storytelling workshops facilitated by the Re•Storying team in Canada, England and New Zealand. This brought storytellers together in a 4–5-week online synchronous workshops with 1-1 support in between to create first-person short films about their experiences (Douglas, Rice, et al., 2021). Multimedia stories made in our workshops often combine voiceovers (narrations) with visuals, soundscapes, and more (e.g., photos, video clips, artwork, music, utterances, gestures). The team provides storytellers with access to filmmaking software, video editing support and help with images and soundscapes. Workshops often include, too, an in-depth framing of workshop themes or issues (co-led by researchers and community members). The method itself is iterative and processual. It is shaped by both the makers and the stories they create in each of our workshops (see Douglas, Rice, et al. 2021; Re•Storying Autism Writing Collective 2022; Rice et al., 2020).. In the Spinning Plates workshops, the process was unexpectedly changed by sibling story creators.

Moving Off Script: Towards Metodologia Otra

As we approached the digital storytelling phase, the team in Canada was preparing for a new group of storytellers. At this stage, we were following the ‘method’ we had previously developed, making assumptions that this would work again with a different group of people. We had led groups of online storytellers through the storymaking process multiple times since 2020, and felt well-prepared for any contingency, constructing a storytelling curriculum and flexible model of support based on 4 weekly group sessions, 1-1 support sessions with facilitators as needed in between and a final story screening after the completion of the workshop. It was not until our plans began to unravel that we turned to the principles of metodologia otra to re-imagine ways of working, indeed our welcome on the sibling carer workshop website emanated our confidence,

> Welcome! We are glad you are here and are very excited to be here too.
>
> Our *Tired of Spinning Plates* storytelling workshops are being held over 4 Saturdays starting on Saturday January 13th, 2024 from 2-4 pm.
>
> This website is a hub where you can find online resources to help you complete your story.
>
> You can also book 1-1 sessions with our amazing team of facilitators who are here to help you every step of the way to make your digital story.

The planned curriculum followed a typical Re•Storying workshop process:

Week 1 Saturday January 13th, 2-4 pm Welcome and Introductions

> Welcome from Patty and Katherine.
> Group introductions - meet your facilitators and introduce yourselves - if you like, feel free to share what brings you to the workshop today, along with a hope and a worry (if you've got one)
> Digital story introduction - we will share a few videos made in past workshops and give you an overview of the digital storytelling process
> Story development - we will do a brief exercise together to help you develop your story idea
> Check out - how you are feeling leaving the workshop and follow up for next week

Week 2 Saturday January 20th, 14 2-4 pm Story Circle

> Check in
> Story circle - this is a time to share your story idea and to ask for feedback from the group that is most helpful to you

Brief orientation to WeVideo - signing up for a seat in WeVideo and the basics with facilitators

Check out - book any 1-1 sessions you need with facilitators

Week 3 Saturday January 27th, 2-4 pm Recording & Images

Check in - where is everyone at with their story scripts and ideas, and thinking together about audio and visual

How to record your audio in WeVideo - online tutorial available

Tips on how to incorporate video and images into your story - Sara Wilde and Sheryl Peters

1-1 or small group sessions booked with facilitators

Book time with your facilitator

Have your images, video and voice over done for next week

Check out - anything you need for next week

Week 4 Saturday February 3rd, 2-4 pm Story Screening

Check in - where everyone is at with their videos

1-1 or small group sessions booked with facilitators

Book time with your facilitator

Have your images, video and voice over done for next week

Check out - anything you need for next week

Story screening Date TBD

Story screening - everyone who wants to can share their finished story or works in progress

Group debrief and feedback (as desired)

Saying good-bye and follow up

The parent-carer workshops largely followed our learned script. This included offering as much flexibility for participation as we could with one-to-one support outside of meetings at a time that suited people. For several weeks after the workshops finished, we carried on meeting for a chat and catching up with each other.

However, we knew, when only one person turned up to the online meeting despite several siblings having ‘signed up’, that our typical 4 week curriculum, synchronous group sessions and 1-1 sessions in between group meetings would not work. We needed to pivot and create a different approach to digital storytelling methods that would meet sibling carers where they were - not where we imagined them to be (Harari and Pozzebon, 2024).

Instead, we worked with siblings individually, meeting with them at dates and times that fit in with their schedules, and without any online group meetings.

This shift, and sibling carer challenges to our methodological design—as flexible, iterative, and affirming as we tried to make it— led us to think about the practices of what became an asynchronous approach to digital storytelling through the principles of metodologia otra (Harari and Pozzebon, 2024):

1) Learning to unlearn

We have come to understand our going off script and shifting the approach away from synchronous online digital storytelling, which depends on weekly group sessions, to an asynchronous form as drawing on a ‘learning-unlearning-relearning path’ (Tlostanova and Mignolo, 2012:14), with the slightly different focus of learning, unlearning and doing differently. This tweak is to remind us that there will always be instances in research where the design does not fit. Central to this alternative path is a rejection of the assumption of the primacy and singularity of “Western knowledge” and its imagined research subject, who is presumed to be available to university-centered knowledge production operating on neoliberal time (Re•Storying Collective, 2022); instead, learning, unlearning and doing differently centres an openness to ‘knowledges’ and alter ontologies like gendered care generated through lived experiences by marginalised people (Tlostanova and Mignolo, 2012). Tlostanova and Mignolo (2012) argue the concept of learning to unlearn has the potential to disrupt the taken-for-granted assumptions about knowledge production emanating from global North contexts, as well as the global South it originated in.

Harari and Pozzebon (2024) describe how, from a decolonial lens, it is important to recognise that research often starts from a colonizing perspective, which imposes Eurocentric race, gender and ability hierarchies, medicalises and pathologises disability as deficit, prizes individualism and economic productivity and erases and marginalises Indigenous, Black and other alter worldviews and experiences that centre relationality, care, reciprocity and participant control in knowledge production (Ineese-Nash, 2020). In the storytelling workshops with siblings, we needed to recognise our epistemological and methodological assumptions were not a system or rules that *had to be* followed, rather we *had to* move beyond our usual methodologies and imagine ways of working that embrace different forms of knowledge and knowledge production (ibid.). In other words, in the process of making digital stories with siblings, we learned that we had to let go of our prescribed working and unlearn the previous scripts while also reflecting on our unquestioned adoption of them. This was not the first time that we had had to 'move off script' in the project. Family carers had already rejected surveys as an appropriate method for understanding their experiences. Following an ethics review, we co-created an online exhibition where family carers could share exhibits in the form of poetry, writing, film, photographs and artwork (Runswick-Cole et al., 2024b)..

Again, we had to interrogate our assumptions about the methods we use. We had fallen into the trap of thinking that workshops require synchronous engagement by participants working with a group of peers, because this is how they worked in the past. Sibling carers changed how we thought about creating space for people to tell the stories in the ways they wanted to tell them. As Harari and Pozzebon (2024: 74) argue, "[i]t takes courage to adopt disobedient practices and create emancipatory methodological alternatives." And yet, without moving off script, we would have failed in our ethical and political responsibilities to the storytellers and closed down an opportunity to think about new ideas and practices in research. We would also have failed to deliver our funded research obligations which also introduces an inevitable and yet rarely acknowledged strand of self-interest in research projects.

2) ***escrevivência*****/writing-living**

We have come to think about digital stories as *escrevivência* [writing-living]. Oliveira et al. (2023) credit the concept of *escrevivência* to Conceição Evaristo (2020a). Evaristo describes *escrevivência* as a writing about oneself and about one's own experiences. And, although *escrevivência* emerges from lived experiences, Evaristo argues that writing-living is neither narcissistic, nor is it an end in itself, rather it speaks to collective experiences of marginalisation. *Escrevivência* is political and disruptive writing which can open up new perspectives and new ways of being in the world (Oliveria et al., 2023). Crucially, *escrevivência* is understood as a way 'to endure' the world and 'to engage' with it (Oliveira et al (2023, 7). In thinking with this concept, we do not wish to erase the experiences of Black, Indigenous and people of colour or to suggest that the experiences Evaristo describes are 'the same' as those of family carers and people with learning disabilities in the global North. Rather we want to recognise the explanatory power of theory generated in the global South for understanding the lives of marginalised people in the global North. Thinking with these theories, we also recognise the parallels between systems of domination forged in the global North by colonial powers imposed on the global South through imperialism and colonisation, signalling the need for a global disability politics of care emphasizing alter knowledges, relationality and participant-driven research.

Returning to the story introduced at the beginning of this article, we can read Emily's story as a story about herself and her own experiences, as well as a story about a collective experience of fear for the future. Her story is political and disruptive writing which offers a way to understand and endure the world as it is and to imagine a world otherwise - a world in which people with learning disabilities and their families are haunted by the spectre of inadequate services and support yet hold the intimate knowledge about their loved one and about care that values difference and relationality. When Emily says she thinks 'of the future every day', she echoes research findings that tell us that siblings of disabled children worry about the future for their sisters and brothers, and their parents (Meltzer, 2017; 2018). Emily's worries for the future are about herself and her own experiences, but speak to collective fears and worries about the support available to people with learning disabilities and their families (post) COVID and in a context of austerity (Flynn et al., 2022) as well as to the possibility of collective resistance.

3. Interculturality

In their discussion of metodologia otra, Harari and Pozzebon (2024) explain the importance of dialogue to open up the possibility of reimagining and transforming the world around us (Freire 2014a,b). Crucially, they understand dialogue as a process that allows people to speak 'together with' rather than one group of people speaking 'for' them. The desire to speak 'together with' rather than ‘for’ family carers and people with learning disabilities is at the heart of the digital story telling method (Rice et al, 2020). And yet, we agree with Harari and Pozzebon (2024) that dialogue is not always enough to change structures and the conditions of power that maintain inequality and discrimination. Harari and Pozzebon propose the idea of interculturality as: “a political, social, epistemic, and ethical project aimed at structural and socio-historical transformation based on the construction by all of a radically different society” (Harari and Possebon, 2024: 73). As a methodological orientation, interculturality means flattening hierarchies and ensuring that everyone’s views are heard.

In the project as a whole, we sought to ensure people’s views were heard: we worked with family carers and with people with learning disabilities to develop the proposal and at each stage the work was guided by the Tea and Cake public involvement group made up of family carers and people with learning disabilities. However, the academics introduced the idea of digital storytelling as a method that holds space for people to tell their stories in a different way and opens up possibilities for communicating differently.

The family carers who participated in the film making told us it was important to them that their stories could be shared widely and that there was the possibility for some form of social and political transformation. To this end, the digital stories are hosted on the Social Care Talk platform. This website provides in-depth information about people’s experiences of social care with the aim of ensuring that people feel less alone and better prepared to navigate health and social care systems. Several films are part of a resource which we have developed for health care practitioners. As a team of academics, people with learning disabilities and family carers, we continue to work together to develop resources to guide practice and to disseminate these widely. So far, we have shared the stories with people with learning disabilities and family carers, academics, activists, practitioners, politicians and policy makers. Unsurprisingly, the audiences often have a strong affective response to the digital stories.

4. *Corazonar/sentipensar* - thinking-feeling

The digital stories are threaded through with emotion. Harari and Pozzebon (2023) suggest that affectivity is one of the main elements in a metodologia otra citing Santos (2018: 101) who describes *corazonar,* reasoning with the heart, as “the act of building bridges between emotions/affections, on the one hand, and knowledges/reasons, on the other. Such a bridge is like a third reality, that is to say, a reality of meaningful emotions/affections and emotional or affective ways of knowing.” Corazonar is closely connected to *sentipensar - thinking-feeling.* Harari and Pozzebon (2013: 17) credit Fals Borda (Fals Borda, 2015) with having coined the term “thinking-feeling” or “sentimentality,” to refer to those “who combine reason and feeling to produce knowledge.” As Santos (2018) argues, epistemologies of the North are so often grounded in the idea of the rational subject they leave little space for the emotions and affect. Metadologia otra allows us to embrace the affective power of Emily’s story, and to understand digital storytelling as an opportunity to create a space where reason and feeling combine to produce knowledge.

Returning to learning to unlearn and doing differently - storytelling with people with learning disabilities

In our original project design, we planned to bring together a group of people with learning disabilities and family carers to guide the research in the Tea and Cake Group. And yet, we had planned only to create stories about care with family carers. In our conversations with family carers and with people with learning disabilities, we learned to pay better attention to the messy and relational nature of care and the care that people with learning disabilities themselves give (Runswick-Cole et al., under review; Ward 2005; 2011). These conversations led us to stray again from our planned path. Three members of the Tea and Cake group , who are people with learning disabilities, chose to tell their own digital stories. We gained an ethical amendment to allow for this as we set off again on a path of learning to unlearn to do differently. By this time, chastened by our initial and careless exclusion of people with learning disabilities from digital storytelling in our research design, we knew we needed to create new scripts, and new ways of doing this. Two members of the academic team, Martina and Martha, worked with Anup, Louise and Stuart to create their stories of care.

Martina, and Martha met with Anup, Louise and Stuart in person and shared a selection of the sibling and parent carer films with them. The group talked about each of the films and the different starting points each filmmaker used in establishing something that mattered to them about their experiences of care and caring. This scaffolded the generative discussion with the group about moments that mattered and their experiences of their caring relationships. Working together through conversation, notes were made and were refined and edited until a finalised script was agreed. The choice of images and the formatting of images with the recording was agreed in conversation together. The film makers gave feedback and final edits agreed prior to the film release. We have described this work more fully elsewhere (Runswick-Cole et al., under review).

All the stories created during the project are available on the Social Care Talk website.

Conclusion

We began this paper with a story about love, care and disability (Smith et al., 2025). We then described the context in which the stories were generated and reflected on what we have learned and unlearned about storytelling in the process drawing on the principles of metodologia otra. We have learned we need to be open to different ways of working in health and social care research and always be prepared to question our assumptions and scripts. People with learning disabilities are consistently excluded from research participation, indeed ‘learning disability’ is used as a largely unquestioned exclusion criteria (Spaul et al., 2020), and yet it was only through discussion with the Tea and Cake group and in learning from the family carer participants that we were able to reflect, and act, on our exclusionary practices in relation to the experiences of people with learning disabilities. Drawing on the principles of metodologia otra has offered us new ways of thinking and working together to explore what matters to people in caring relationships with one another in a way that matters to them (Runswick-Cole et al., 2024a).

We call for an openness and flexibility in digital storytelling methods, that allows not only for synchronous and asynchronous online storytelling but which opens up the possibility of a multiplicity of ways of doing digital storytelling differently - ones yet to be imagined or to be learned to unlearn and to re-learn. We argue the principles of metodologia otra offer a way of opening up research methods in health and social care research more broadly. This will require humility and courage on the part of researchers who may need to abandon their tried and trusted approaches to do things differently. In an international context for health and social care research in which both ‘involvement’ and ‘inclusion’ are now prioritised by the research funder (National Institute for Health and Care Research, 2024a; 2024b), it is important that they too recognise that is it only by moving off script that researchers can offer an ethical response to storytellers who want to tell their own stories in their own ways. Inter/nationally, health and social care researchers are constrained by the policies, practices and expectations of the systems they work in. It is only possible to follow a learning-to-unlearn-to-doing-different path if research systems, including universities and research funders, also embrace the opportunities and possibilities of doing research differently.

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