

# Giving Care a Platform

## The Use of Instagram by Mothers of Children with Chronic Illness

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### Abstract

In this article, we explore the ways that the social media platform Instagram shapes the intersubjective experience of caring for children with chronic illnesses. Based on long-term immersive social media research and in-depth interviews with women maintaining popular Instagram accounts dedicated to caring for children with chronic illnesses, we approach Instagram as a ‘moral laboratory’ (Mattingly 2010) in which caregivers negotiate the meaning of their present experiences and experiment with potential futures for themselves, their children, and their relationships together. Through a consideration of the role played by Instagram in mediating the forms of affective labour these mothers engaged in, we consider how the very features that make Instagram a resource—its ability to foster a sense of social connectedness, validate their invisible labour, and provide practical knowledge—both create new and intensify longstanding forms of pressure and anxiety in their lives. We regard these Instagram feeds as complex social settings that are playing an increasingly important role in the trajectory of lives of people with chronic illness and their caregivers.

### Keywords

Social media, Instagram, Caregiving, Chronic illness, Children.

## Introduction

A photo of three-year-old Fiona<sup>1</sup> sleeping depicts a rare quiet moment in the young girl's life growing up with Down Syndrome. More photos surround it, capturing Fiona as she dances, poses for the camera, practises speech therapies, and waits at the doctor's office. These images of childhood intimacy reside not in a family photo album, but rather on her mother's Instagram page, which has more than one hundred thousand followers. Underneath the photo of Fiona curled up on the couch, Fiona's mother, Shannon, writes:

I'm not sure if you'll ever know of this account. As I watch you sleep on me, I go back and forth about it ... I started this to find my bearings at a time when I felt like I was twisting in the wind ... to make peace with our new life. With her diagnosis. I wanted people to just see a baby girl who was loved. I wanted to show it in our daily life without saying in every post 'I love her' and instead seeing it in her pictures and feeling it in my captions.

As this suggests, Shannon uses Instagram as something more than simply a venue for sharing her daughter's life. In the stream of images and text that comprise Shannon's Instagram feed, users find a mother's evolving struggle in the face of a radically transformed life and understanding of motherhood. Instagram offers an interactive setting to both enact the immediacy of her love for her daughter and reflect on her own experiences as a mother and caregiver for a child with Down Syndrome. Shannon is only one of a growing number of mothers of children with complex medical needs who post intimate details of their and their child's lives on Instagram to a large following.

In this article, we explore the distinctive ways that social media platforms such as Instagram shape the intersubjective experience of caring for children with chronic illnesses. Based on long-term immersive social media research and in-depth interviews with women maintaining popular Instagram accounts dedicated to caring for children with chronic illnesses, we approach Instagram as a 'moral laboratory' (Mattingly 2010) in which caregivers negotiate the meaning of their present experiences and experiment with potential futures for themselves, their children, and their relationships together. We argue that the visual focus, on-the-go accessibility, and connectivity of Instagram plays a constitutive role in shaping how care is imagined and enacted by these mothers. Through tracing how 'online' and 'offline' lives influence one another, we consider how the very features that make Instagram a resource for these mothers—its ability to foster a sense of social connectedness, validate their invisible labour, and provide practical knowledge—also create new and intensify longstanding forms of pressure and anxiety in their

<sup>1</sup> All names are pseudonyms. This study received ethical clearance from the Amherst College Institutional Review Board. Data collection was carried out between August 2018 and July 2019.

lives. As such, we regard these Instagram feeds as complex social settings that are playing an increasingly important role in the trajectory of lives of people with chronic illness and their caregivers.

## **Instagram as Laboratory: Social media and chronic illness**

While biomedical explanatory models of chronic illness and disability give primacy to the individual body, anthropologists have long framed chronicity as an inescapably interpersonal and social experience (Kleinman 1988; Becker 1997; Manderson and Smith-Morris 2010). Anthropologists have drawn particular attention to how individuals with chronic conditions and their families manage daily lives infused with uncertainty and the potential for crisis (Kleinman 1988; Frank 2013). In so doing, they have challenged how clinical frameworks approach illness as unfolding across distinct stages—moving from diagnosis to treatment to cure—and instead underscore how chronicity does not offer a clearly defined endpoint (Jain 2007). At the same time, anthropologists of digital media have come to recognise social media as a valuable resource for individuals with chronic illness. Engaging important themes within the anthropological study of social media—such as its role in negotiating people’s understanding of self and society (Pertierra 2018; Turkle 2011), online and offline relationships (Baym 2015), and how these vary depending on the social and historical contexts of users (Miller et al. 2019)—these researchers have explored the evolving impact of social media on the experience of chronic illness, both of patients themselves and of their loved ones. They have considered, for example, how social media (and online support groups) foster participants’ ‘collective intelligence’ (Radin 2006) that, in turn, leads to new approaches to care in both online and offline spaces (Thomas 2017; Page 2012; Phillips and Rees 2018; Kingod 2020; Egger 2019). Building on recent anthropological interest in care and caregiving (Kleinman 2019; Stevenson 2014; Mol 2008; Mol, Moser, and Pols 2010; Glenn 2010; Aulino 2019; Buch 2015), we extend this interest in chronic illness and social media to consider the experiences of full-time caregivers of young children with chronic conditions. In other words, this article explores the platform-specific implications of social media for practices and experiences of caregiving.

As we charted the growth of the Instagram feeds of the women interviewed for this study, it quickly became apparent that Instagram was not merely a technology for sharing experiences, but one that was also constitutive of particular kinds of experience. In the ways in which Instagram can both convey and constitute experience, we have found Cheryl Mattingly’s concept of ‘moral laboratory’ to be particularly useful in analysing the role Instagram plays in our interlocutors’ efforts to make sense of their new lives. Building on her longstanding interest in narrative

as an ‘open ended process that is always working to locate desired futures’ through the weaving together of granular experiences to reveal larger meanings embedded in daily life (Mattingly 2010, 45; see also Good 1993), Mattingly (2013) has more recently explored the ways that the everyday lives of families caring for children with chronic illness can be generative settings for moral becoming. For Mattingly, this terrain of the everyday, as a ‘moral laboratory’ is ‘a metaphorical realm in which experiments are done in all kinds of places and in which the participants are not objects of study so much as researchers or experimenters of their own lives—subjects and objects’ (idem, 310). Daily care thus emerges as a space of experimentation and world-making, where ‘the “new” is inaugurated ... the possible pitted against the predictable’, and where individuals work to create, revise, and critique their self and world view (Ibid.).

In this article, we take Mattingly’s lead to explore the role played by Instagram in the conceptualisation of everyday care as a space of experimentation and becoming. That is, we are interested in how the visual focus, on-the-go accessibility, and social connectivity of Instagram, together with the forms of self-presentation it fosters, gives rise to a distinctive sort of moral laboratory for the mothers caring for chronically ill and disabled children. Instagram posts, as demonstrated in the examples below, are visual tools the mothers use to grapple with the significance of particular moments in their lives and to see their experiences as part of a larger narrative arc pointing towards the future that they desire for themselves and their child.

Appreciating social media as a moral laboratory in the lives of the mothers interviewed for this study requires differentiating Instagram’s platform vernacular—its ‘unique combination of styles, grammars and logics’ (Gibbs et al. 2015)—from those of other social media platforms. Instagram’s most distinguishing feature is its visual focus: users generate content by posting photos and videos with accompanying captions (van Dijck 2009). A user’s posts can then be viewed, liked, and commented upon by other users who choose to ‘follow’ them on the platform (Sheldon and Bryant 2016). Each user has a page that is home to their own posts which are presented in reverse chronological order, with the most recent posts appearing at the top of the user’s page, aiding in the sense that users are creating a visual chronicle of their life and Instagram identity in time with their evolving present (Page 2012, 13). Another important feature of Instagram is its immediacy and mobility. An application created for mobile ‘lifestreaming’, Instagram allows individuals to post in the midst of their everyday routines (Gibbs et al. 2015; Marwick 2013, 208). Unlike Facebook, Twitter, and YouTube—which began as internet websites—Instagram started as a mobile device application. Its features, including temporary ‘stories’ that disappear after 24 hours, reflect its mobile origins and are specifically crafted to enable both on-the-go posting and more curated

content. As we will consider in detail, Instagram's visual focus, temporal structuring, mobility, and capacity to foster connectivity lends itself in unique ways to transforming everyday acts of care into settings of personal, relational, and narrative becoming.

In order to explore these themes, I (Mikayla Gordon Wexler) observed and analysed seven mothers' Instagram pages over the course of a year and a half, immersing myself within the everyday and interpersonal flow of their online worlds—what anthropologist Renato Rosaldo characterised in 1994 as 'deep hanging out' (cited in Clifford 1996). Through Instagram's search tool and snowballing methods, I selected a sample of 10 Instagram users who had at least six months of posts related to their experiences of caring for their child with chronic illness and at least 2,000 followers. I contacted each of these users through Instagram's user-to-user messaging service. Of these users, seven mothers consented to one semi-structured interview. The mothers interviewed were all between twenty-five and forty years old and primarily from suburban areas of the United States. Apart from two mothers who had step-children, their child with a disability or chronic illness was their first. The children have a wide range of diagnoses, including spina bifida, hydranencephaly, Type I diabetes, Down Syndrome, Cornelia de Lange Syndrome, lymphatic abnormalities, and complications resulting from a premature birth. While all but one of the women were married, many of their husbands travelled full-time for work, leaving them as primary caregivers for long stretches of time. The gendered use of Instagram aligns with Sheldon and Bryant's (2016) findings that women more actively post about personal experiences on social media. While the mothers expressed using other forms of social media, such as Facebook, for connecting with friends and relatives, they emphasised that Instagram was their primary platform for sharing information about their child and caregiving. Thus, we chose to focus on Instagram for analysis of their social media experiences. The Instagram stories we explore are not fictional worlds created merely for the pleasure of their followers, but the everyday experiences of families whose lives are not limited to Instagram. For this reason, while many users have public Instagram pages, we chose to only include Instagram data from the same users who formally consented to be interviewed (see Kingod 2020).<sup>2</sup>

2 Despite efforts to include a wide range of voices, most of the individuals in the community of networked pages who responded to my request for an interview were White, cisgender, middle- and upper-middle class women involved in heterosexual relationships. Beyond limiting the sorts of conclusions we can draw from this research, this raises critical questions about Instagram more broadly. Although a free platform and ostensibly accessible to anyone with a computer or mobile device, the profile of our interviewees suggests that not everyone is able to find a voice and an audience on Instagram.

## Experimenting with life after diagnosis

Corey was born four months prematurely and immediately diagnosed with cerebral palsy resulting from periventricular leukomalacia (PVL), a type of brain injury. He stayed in the newborn intensive care unit (NICU) for almost a year—an experience his mother, Nicole, describes as a constant search in the dark for information: ‘While we were in the NICU, I was trying ... to find something, someone, some resource to give me an idea of what our life would look like. And I wasn’t really finding that, and I also probably did not even know what I was looking for either.’ In learning about her child’s diagnosis, Nicole, as with all of the other mothers interviewed for this study, struggled with both the immediate loss of the future she had imagined and the subsequent inability to find any new narratives to grasp onto as she tried to make sense of her changed world. Shannon echoed the grief embedded in this experience to me:

With typical kids ... you don’t realise that your expectations are wrong until much later in life. But for me, I had to change my expectations immediately and that is saying that I stopped having any ... I wasn’t looking for black and white facts [at the hospital], I was looking for what is different for someone that has a child with Down Syndrome?

Though their children’s doctors offered them timelines and statistics, the mothers could not depict the life that would form around their children’s diagnoses. Their lack of lived knowledge only heightened the uncertainty and anxiety that came with their new role as mothers. Ari, reflecting on the days after her son, Nicky, was born with a lymphatic malformation (a rare disorder leading to a disfiguring mass, breathing and feeding challenges, and chronic pain), ‘You feel like you have no control over your child’s life. I was scared [Nicky] was confused, because of all the nurses and doctors taking care of him, [about] who his parent actually was.’

Rather than resign themselves to loss and uncertainty, the mothers struggled for a way to control the shape of this new experience. Instagram emerged as a useful and accessible resource for achieving this, as it allowed them to document their experience exploring, learning, and refining their understanding of how to care for their child. As Shannon states, ‘My [Instagram] account is not just about Down Syndrome, or parenting, or parenting a child with a disability. It is about being human and trying and failing, trying and succeeding. It is about understanding my growth.’

In this regard, the mothers’ Instagram feeds become moral laboratories where they work to frame their experiences with their child in their own terms, rather than relying exclusively on clinical frameworks or ableist social norms about ‘typical’ or ‘normal’ kids. These mothers were also drawn to Instagram because it was able to

capture how their experimentations developed through time, and thus convey the emergent qualities of caregiving. As anthropologist Annemarie Mol observes in her writings about care and chronic illness, '[W]hat it is to do good, what leads to a better life, is not given before the act. It has to be established along the way' (2008, 75). The work of 'attuning the many viscous variables of life' is a cyclical process, one without neat or necessarily intended definitions or moments (idem, 54). Instagram proved to be uniquely suited for the indeterminacy of care that now consumed their lives.

This work of attunement and reframing is apparent on Nicole's Instagram feed. Almost two years after Corey's premature birth, Nicole's Instagram page has hundreds of posts. Many of the most memorable photos are graphic—Corey in the NICU, his small body hidden underneath tangles of tubes and monitor wires. But interpolated between these images is a photo that depicts something more mundane, yet no less significant: Corey playing with a toy in a grocery store cart. The perspective of the photo shows that Nicole is not holding onto the cart as she takes the picture and Corey appears so relaxed and distracted by his toy that he does not even look up at the camera. Accompanying the photo is the following caption:

This may look like an everyday occurrence. A little boy playing in the cart while his mom shops with both hands. However, this is something I have only been able to watch from afar and hope would be in my future. I have always done my grocery shopping without Corey or when I have someone to help push Corey in his stroller. Today is a huge first.

Nicole acknowledges that to an outsider this is far from remarkable, but for Corey, whose diagnosis of cerebral palsy makes sitting up difficult, this is a significant accomplishment. This one caption and photo represent for Nicole years of worry and uncertainty about what Corey might accomplish. It is also a visual validation of all of the work Nicole has put into helping Corey improve his spinal strength through therapy. Although this post may seem like a small step within the grand scheme of childhood growth and development, Nicole conveys a sense that this moment opens up a new set of possibilities for her to embark on with him, thereby marking a shift in their relationship and the life that they share together.

These feelings of achievement, however, are often fleeting. The next photo on Nicole's page, posted only a few hours after the grocery store, shows Corey on a mat in his therapy room with what appears to be liquid food splattered across the floor. In the caption, Nicole jokes, 'Coming off my new shopping high like ... [annoyed face emoji]. Sometimes Corey's blend sprays out of his G-tube instead of going in ... #gtubelife #feedingtubeawareness.' Nicole explained in her interview that feeding Corey is one of her biggest anxieties. Preparing the G-tube is a skill

that has taken her more than a year to even begin to master, and Corey continues to throw up his food regularly. In this regard, Instagram is also a place for capturing her struggles with her responsibilities. ‘Instagram has become my place to vent’, she explained in our conversation, ‘it helps me to just keep from crying in the moments that are most challenging’.

Nicole and the other mothers must face the unexpected every day when caring for their children. Sometimes their children do not reach milestones when their clinicians say they will, but at other times they exceed clinical expectations. Yet, these moments of friction between expectation and reality do not occlude the mothers’ ability to move forward. Instead, as Mattingly explains, moral experiments are ‘only of *narrative* import if there is suspense about the outcome and that means some hope for success, some reason to take a risk’ (1994, 70). On Instagram, the mothers manage this dissonance by creating a concrete, visual archive of their child’s progress and shifting definitions of their child’s illness identity and experiences from clinical rhetoric to their own. Quite literally, the mothers use Instagram to zoom out from the seeming stagnancy of everyday life and bring into view the larger arc of their child’s perseverance and growth. For instance, Instagram gave Nicole a way to pause and reflect on the significance of Corey’s smaller moments, to show to herself that Corey sitting in a grocery cart is something worth attending to and sharing with others.

Nicole uses her Instagram post about the grocery store as evidence that she is progressing towards a desired, if uncertain, future. In this way, the Instagram post becomes more than Nicole’s passive observation. Instead, she is actively experimenting with the framing of her experience, which ultimately cultivates a sense of growth and accomplishment that allows for her to see her subsequent failure to feed Corey as a bump in the road rather than an insurmountable barrier to a hoped-for future. This becomes even clearer in the posts following Nicole’s original grocery store announcement. There are more photos of Corey in grocery carts, but now the captions are shorter and more mundane. The most recent photo jokes about how Corey prefers Trader Joes over other stores—without any special mention of how Corey is sitting perfectly upright in the photo. An event that was once dramatic or seemingly impossible is now recognised as normal, and Nicole learns that even when she cannot see it in the day-to-day, Corey is progressing at his own pace. Nicole continues to push herself to expand her expectations about what she can help Corey accomplish.

By posting their everyday experiences on Instagram, the mothers interviewed for this study test out framings of their identity and experiences as caregivers, which subsequently reconfigure the shape and meaning of their actions and their perspective on their child’s illness. Put otherwise, they use Instagram as an



adaptable stage upon which they can enact negotiations of offline aims (Baym 2015; Turkle 2011; Gershon 2014). In so doing, their detailed documentation of mundane domestic activities and highly repetitive and technical acts of caregiving are transformed into vital ‘moral laboratories’. Such moments become significant markers of their child’s progress, the value of the mothers’ everyday caregiving, and the potential futures for their child that may not be included in clinical predictions. In the process, as we turn to in the following section, the mothers become immersed in a social world on Instagram that both makes their experimentation collaborative and helps to legitimise their caregiving as valued labour.

## **Resisting invisibility, co-creating futures**

For most of the women interviewed for this study, the birth of their children meant an exit from the labour market. These mothers had the financial resources to become full-time caregivers and saw the taking on of this role (instead of their husbands doing so) as an obligation rather than a choice. ‘Obviously I cannot work anymore, I need to stay home with my daughter’, Rachel, the mother of Alice, a young girl with Type I diabetes, explains. Laura, Chase’s mother, echoes that quitting her job after Chase was born with spina bifida was ‘a no-brainer’. Although a ‘no-brainer’, this decision also carried with it a set of ambivalent feelings common to middle-class norms regarding family, work, and self-realisation. In keeping with their backgrounds as White, middle-class professional women, their sense of personal worth was closely tied to their professional lives. They understood that deciding to leave the workforce—possibly forever—in order to care for their children meant that they would work harder and longer than they had in their jobs, but that the work would probably not be valued as productive labour. Leaving their jobs would also entail the loss of a life dense with social relations tied to work, to be replaced by a ‘private world of family and personal relationships’ (Daniels 1987, 408) where they were expected to have the natural predilection to fulfil heteronormative roles—making career adjustments in order to be ‘an “anchor” for the children’ (Glenn 2010; Lareau 2011, 51). In this regard, they were aware, at least intuitively, of the long history of gendered domestic labour into which they were stepping (see Glenn 2010; Lalvani 2011; Federici 2004). This consignment to a domestic sphere of undervalued labour, together with assumptions by others that their lives were now defined only by grief and loss, generated a profound sense of isolation for these new mothers.

In this section, we expand our discussion of Instagram as a moral laboratory to consider how it not only provided a platform for these women to try out and chart new futures for themselves, but also helped them to revalue their caregiving by both rendering it visible to others and facilitating a sense of social connectedness

and collaboration. In formulating this relationship between social media, sociality, and the valuation of the labour of care, and building on the work of Antony McCosker and Raya Darcy on cancer blogs (2013), we have found it useful to approach these mothers' caregiving and their engagement on Instagram as overlapping forms of affective labour.

The term 'affective labour', conceptualised as a form of 'immaterial labour', emerged out of efforts to make visible the affective, cognitive, and communicative skills that were playing a prominent role in the late-twentieth century transformations in capitalist production, as exemplified in the dramatic expansion of the service and care industries (Hardt and Negri 2004). A range of feminist thinkers in turn have employed the term in order to reframe longstanding debates about domestic and reproductive labour, drawing attention to the ways that domestic labour is affective labour that involves, as Hardt and Negri put it, 'producing affects, relationships, and forms of communication and cooperation among children, in the family, and in the community' (Hardt and Negri 2004, 110; Weeks 2007; Oksala 2016). In our case, we are particularly attuned to the role played by Instagram in mediating the forms of affective labour engaged in by the mothers we interviewed. At the same time that these women find validation and visibility on Instagram for their relentless and exhausting physical caregiving, they are also engaged in the work of building social connections through the complex management of online, interpersonal relationships that produce affective attachments between themselves and their followers.

In tracing the mothers' posts and other users' responses, a world thick with social relationships comes into view. Shannon explained, 'A lot of the time I cannot reach friends that live nearby, my husband is not a talker ... so I turn to Instagram as my outlet ... Seeing other mothers on Instagram was a sign. It was hope. It was knowledge!' Shannon's characterisation of Instagram as a space of both hope and knowledge is important. The mothers interviewed for this study peruse pages and message mothers to find out more about their experiences, to share information on treatments and care techniques and, as Rachel describes, to reassure themselves that they are not alone in their uncertainty:

Through Instagram, I found a lot of moms in the same boat. Some with diabetic kids, others not. But regardless, they know what I go through and the sleepless nights and I see their posts and it makes me realise, okay I am not the only crazy person that is up at three in the morning doing something to stay awake because I am trying to keep an eye on my kid and manage her care. So yes, it does definitely help to see and have support from other people.

Rachel is able to confirm to herself that her practice of staying up all night and worrying over her daughter is not unique or 'crazy', since other mothers on

Instagram tell her that they, too, are awake and grappling with the same challenges. In other users' responses, the mothers also find motivation to continue care work that is often exhausting and demoralising (Kleinman 2019; Sobo 2010). When Alyssa, the mother of Steven, a toddler with Cornelia de Lange syndrome,<sup>3</sup> voices her concerns about him, her posts are immediately saturated with other Instagram users, and mothers, offering sympathy, appreciation, and their own experiences. One mother comments: 'Thank you for always eloquently putting my emotions and thoughts [in]to words. It is both a chosen and forced isolation, but I found so much comfort, support, and encouragement in this post.' Alyssa replies: 'We relate on so many levels. I am right there with you feeling everything that you are. I am always here.' A bit below, another user adds: 'You do not ever have to explain yourself. You are performing the most important job you have ever been given and are doing a fantastic job of it.' On Instagram, caregiving becomes a collaborative experience. The public-facing aspects of the platform transform the mothers' previously invisible caregiving into visual and discursive collaborations that both ease their isolation and project the value of their care.

The ways that Instagram facilitates these forms of sociability and social validation also plays an important role in transforming the mothers' ad hoc efforts to help their children into elaborate therapeutic performances that structure their caregiving labour. Nicole's Instagram page is filled with videos of her and Corey practicing their specific therapy routine:

Today's routine: 90 minutes—stander, 30 minutes—corner chair and work on fine motor skills, 30–60 minutes—M therapy, 30 minutes—feeding, 30 minutes—therapy chair, 30 minutes—stimulation, 2 hours—PT appointment. Total: 4–6 hours. I am getting better at some exercises and learning new ones all the time.

What was originally merely an improvised, private learning of therapy, becomes, through Instagram, a defined 'project' in Corey's development that Nicole shares with her followers. Through watching others and sharing her efforts on Instagram, therapeutic practices and objectives become structured, professional, and quantifiable. Nicole's care and Instagram posts become part of a visual performance, with social media as the 'performative [device] ... [that] prompt[s] or provoke[s] women to act on and through their bodies ... in particular ways' (Johnson 2014, 333). Nicole is committed to making her caregiving routines visible to her Instagram audience by posting videos of therapy every morning, afternoon, and night. She even 'goes live' on Instagram, wherein she livestreams various caregiving routines and techniques and responds to comments from other users in real time. In other words, an initial desire to make her experiences with Corey

3 A genetic disorder that affects cognitive and physical development and causes heart failure.

visible has developed over time into a purposeful form of affective labour wherein she spends time designing posts as a teaching method for others and through which she manages a complex set of relationships and affective ties among her followers.

It is in this regard that we understand the mothers' use of Instagram as cultivating collaborative endeavours that both allow them to experiment with their understanding of themselves as caregivers and to find validation in their labour. Through the domino effect of storytelling that Instagram's platform enables, the mothers are shown that their caregiving is significant labour, that they are seen, and that there are others in agreement with them across diagnoses, contexts, and physical space (Page 2012). As Laura explained: 'It is so easy to give in to taking it easy. But Instagram keeps me accountable for getting Chase out there. It helps my husband and I know we can raise Chase to be confident, independent, and eager to try new things, difficult or not.'

Although the mothers could not possibly know personally all 100,000 users who view their pages, they think of themselves as speaking to individuals who are personally invested in their child's life (Marwick and boyd 2014, 130). In order to build these relationships, the mothers must work to create and maintain their audience. An important aspect of Nicole's experimentation with the framing of her grocery store trip with Corey discussed above is the way that it elicited validation from her Instagram audience's support. The payoff of this affective labour becomes evident as the community and online interpersonal intimacy that they foster, and find, empowers them to imagine meaningful futures for their children that go beyond clinical benchmarks and external definitions. On Instagram, these mothers can find support for their efforts to rework a public discourse that seeks to 'other' and minimise individuals with disabilities or chronic illness as well as their caregivers (Lalvani 2011).

## **The burdens of Instagram**

The very features that make Instagram a resource for these mothers—its ability to foster a sense of social connectedness, validate their invisible labour, and provide practical knowledge—also create new forms of pressure on their lives. In this section we explore how Instagram's on-the-go accessibility and interactivity can intensify the 'sense of relentless responsibility' already common among caregivers of children with disabilities (Blum 2007, 209) and thus redouble the social expectations associated with 'good motherhood' in an era of high-tech home care (Arras and Dubler 1994, 21). Despite Instagram's ability to help them envision, experiment with, and validate futures for their children that don't necessarily align with clinical and societal expectations, we found that there was nonetheless a

pervasive sense among these mothers that they needed to work twice as hard in order to monitor and maximise their child's success and thereby demonstrate that they were good mothers (Blum 2007; Johnson 2014). Instagram intensified the mothers' expectations of themselves, their caregiving, and their sense of responsibility to others.

The pressure these caregivers experience and how this is associated with societal ideals of 'good mothering' is captured in Fiona's mother's discussion of her exhaustion and self-doubt:

I almost cried during therapy ... just about finding a good balance because sometimes Fiona doesn't want to go and I hate that our life has started to be school, therapy, sleep. It sucks sometimes, I'm not going to lie ... I just wish that when Fiona wants to cuddle on the couch with me ... I wish that we could and not have to go get ready or do therapy. But on the other hand, people with Down Syndrome are doing more and the reason is because of therapy and early interventions. ... On top of the daily grind, we are hard on ourselves. Really hard. We worry and wonder if we are doing it right, if we spend enough time with them, if we nurture their independence. We feel Mom guilt at every turn.

As reflected in Fiona's mom's experiences, adhering to therapy, managing medical equipment, monitoring development milestones, and advocating for their child in educational and clinical spaces have become an important way these women prove their worth as mothers (Blum 2007; Glenn 2010). On Instagram, this manifests as a need to be constantly posting and demonstrating their active mothering.

Rachel relies on an app on her phone to monitor her four-year-old daughter Alice's blood sugar levels as part of her Type I diabetes management. In addition to providing real-time notifications about her daughter's blood sugar levels, the app also syncs a graph of Alice's blood sugar from a glucose meter ('pod') on Alice's body to Rachel's phone. Checking and measuring blood sugar consumes much of Rachel's day. 'Every day I am playing with her pod ... I am constantly changing it, tweaking it constantly, tweaking her numbers.' Rachel went on to explain, 'For the most part I am obsessed with her care, and for the most part she has very good control. As soon as I see she is dropping I react, so her [blood sugar] graphs are usually good. I try to post a good graph of her on Instagram every day.' When

Rachel posts Alice's 'good' blood sugar graphs from her iPhone app to Instagram she is praised by other users for her competence.<sup>4</sup>

Rachel's comments convey a general sentiment among the women interviewed: that while Instagram interactively builds social connections and visibility, it also intensifies the expectation that they dutifully enact the 'script of the good mother' (Gabel and Kotel 2018, 180). Rachel, for example, explained that soon after starting her Instagram page other mothers began private messaging her, asking questions about how they can keep their children's sugars as stable as Alice's. Rachel felt that these comments increased her obligation to maintain what she termed her 'obsessive' tracking of her daughter's blood sugar and continual posting of graphs on Instagram in order to confirm the quality of her care, which was also a confirmation of her devotion and worth as a good mother. Rachel's story captures how the vigilant maintenance of Instagram reinforces the pressure the mothers feel in their daily caregiving.

As Rachel's experience also exemplifies, the mothers' engagement on Instagram creates an audience with which they have 'perpetual contact' and for which they also feel tasked with care (Baym 2015; Burchell 2014, 40). For every post the mothers write, they receive hundreds of comments asking for more updates, advice, a widening of the view into their child's life. In response, they try to make frequent and detailed updates, and regularly host question and answer sessions to 'catch up' viewers on the recent events in their child's life and illness. Many of the mothers mentioned receiving concerned and impatient comments when they have not posted in a couple of days. Sarah, the mother of Tina, a two-year-old girl with Pfeiffer syndrome, which affects facial bone structure and hearing, informed me that she 'must make one post a day of Tina or I am messaged, "Is Tina okay?"' Even on days when the mothers feel they do not need Instagram's solace, they still feel pressure to post or else risk the Instagram relationships that they have formed. Ari, Nicky's mother, sounded anxious as she noted: 'We have so many followers that are always asking me to post ... and sometimes I am like, I do not know what else I am going to post today.' This maintenance work becomes a constant strain on the mothers when the mobility and omnipresence of Instagram is taken into account. While Instagram provides the opportunity for constant engagement, it also restricts the mothers' feeling that they can log off or be vulnerable about the more challenging moments of caregiving. At times, it became difficult to determine if the source of the exhaustion described by these women,

4 Rachel's use of this blood sugar monitoring technology can be understood as an example of how caring for disabled and chronically ill children intersects with what Sophia Johnson has characterised as the 'device-ification' of motherhood, wherein technology and data render pregnancy and motherhood as 'an administrative and calculable activity, valuing data over subjective experiences' (Johnson 2014, 341; see also Leaver 2015).

which is common among caregivers, came from the work of caregiving itself or the labour of maintaining their Instagram feeds.

Together with the sense of ‘relentless responsibility’ that comes with caring for their Instagram feed and managing online relationships, the mothers interviewed for this study felt additional pressure to align their Instagram engagement with social media norms of (self-)presentation, including positivity as a marker of adherence to ‘proper’ caregiving (Groenevelt 2021).<sup>5</sup> Steven’s mother exemplifies this tension as she addresses a long break she took from social media in one of her posts: ‘I am sorry I have not [posted] ... [Steven] has to be my priority and when things settle down, I promise to resurface and hope to see you waiting there for me, and for us, with open arms.’ Steven’s mother sees her obligations to remain the ideal caregiver conflicting with the exhausting demands of her child’s illness and the fact that she cannot always be what others on Instagram want her to be. At the same time, losing her audience or the image she looks to uphold as a caring mother is equally paralyzing. Concessions from the women in this study that they sometimes want to give up on their Instagram and even on their care, further demonstrate the gravity of the bind they find themselves in. Every moment where the mothers are not motivated to improve upon their child’s care is seen as a missed opportunity for both their child’s growth and the validation they receive on Instagram. In this light, Instagram comes into view as a technology that facilitates the deepening of gendered divisions of labour by intensifying the caregiving that falls on women’s shoulders.

As these examples illustrate, the continuous technologically induced, platform-specific pressure to maintain one’s Instagram presence thus merges with the affective labour and gendered expectations of motherly care and devotion aiming to bring their child and themselves back into the fold of social acceptance (Gabel and Kotel 2018). In such a setting where patients and family caregivers are already expected to be active and informed ‘consumer-citizens’ (Glenn 2010; Landsman 1998; Gabel and Kotel 2018) and mothers’ ‘moral worth’ turns on their abilities as consumers to access available technologies and expert knowledge to ensure their children’s normative development (Landsman 1998), Instagram presents new challenges to these mothers. While Instagram provides connection and support in this exhausting work, it also challenges their sense of moral worth and generates feelings of perpetual inadequacy. As Nicole explained, ‘I realise there is a small part of me that still feels incapable of producing a healthy and typical child. ... That

5 The desire to render their care publicly visible raises complicated ethical questions. In keeping with the norms and expectations that parents should shield their child from harm online (Marwick and boyd 2014, 1052), these parents are expected to adhere to standards of ‘privacy stewardship’, where they decide what is appropriate to share about their child (Kumar and Schoenebeck 2015, 1302). For mothers specifically, this assumption stems from the disdained concept of ‘sharenting’: where mothers are viewed as over-sharing information about their child to the point where every aspect of their life is incorporated into their digital identity (Blum-Ross 2015; Leaver 2015). Even as the women felt they were managing their child’s care well, they were subjected to judgement from other users.

is how deeply ingrained the thought, idea, or delusion of what a mother is and should be is in me.’

## Conclusion

Building on Mattingly’s insights about moral experimentation (2010), we see Instagram as both a visual and embodied tool for caregivers to make new meanings out of present experiences and to take an active role in charting new futures for themselves. When the women in this study are up early practising therapies or lying awake in the middle of the night waiting to hear the alarm of a breathing or blood sugar monitor—the moments when they feel most intensely alone—Instagram provides not only social connection but a virtual laboratory where they can experiment with how they see their care, their relationship with their child, and their child’s future. The affective labour the women sustain to create their Instagram page forges meanings and connections that become a resource for enduring by reminding them that the care they provide matters; that they and their children matter. Yet, this laboratory for possibility and connectivity carries with it added burdens. As our research demonstrates, with the sense of social connectedness and validation that Instagram fosters among mothers caring for children with disabilities and chronic conditions comes a sense of relentless responsibility, which further intensifies the burdens of gendered notions of caregiving. In exploring these tensions between possibility, responsibility, and burden, the experiences of the women interviewed can help us expand our understanding of what Arthur Kleinman calls the ‘moral core of caregiving’ (2012)—the ways that care can become expansive by cultivating deeper relationships, building knowledge, and making individuals more attuned to each other and to the world around them.

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