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'Life of Lola'

A commentary on graphic anthropology

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ABSTRACT | In this paper I present an ethnographic comic that illustrates two points: the social life of diagnosis following newborn screening for the metabolic disorder MCADD, and the concept of 'shadow habitus' in relation to chronic illness. I then deconstruct and interrogate the process of creation behind the comic, asking what this reveals about knowledge creation and ethnographic practice. Using a three-part framework, I argue that a graphic narrative can show complex theoretical concepts in medical anthropology, that it is collaborative and relational, and that it is a tool for thinking critically through and about ethnography. I use this example to show how graphic anthropology opens and makes accessible new ways of thinking and framing illness, health and dis-ease – to ourselves, to our peers and to a non-academic audience.

Keywords: graphic anthropology; shadow habitus; comics; ethnography



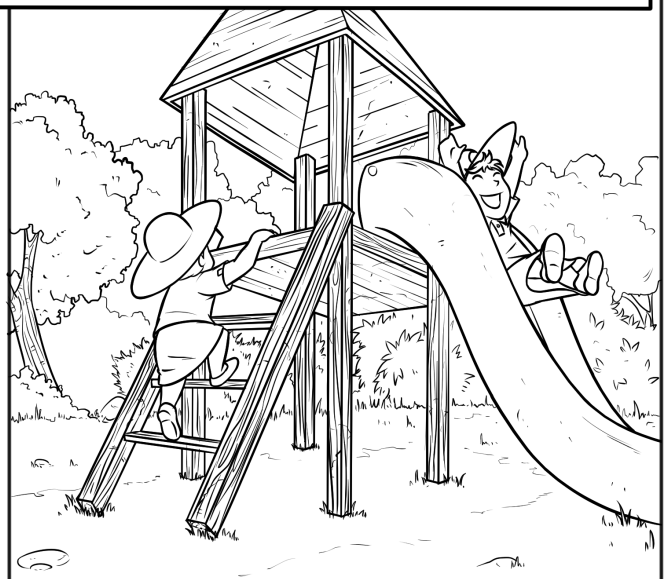
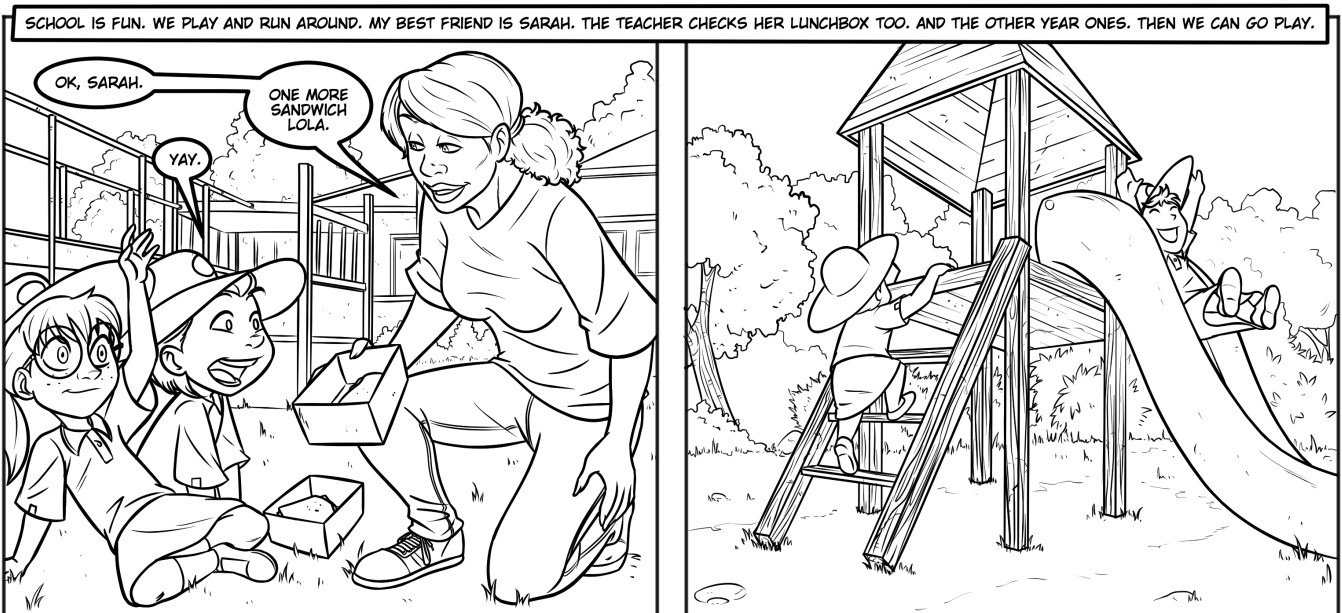
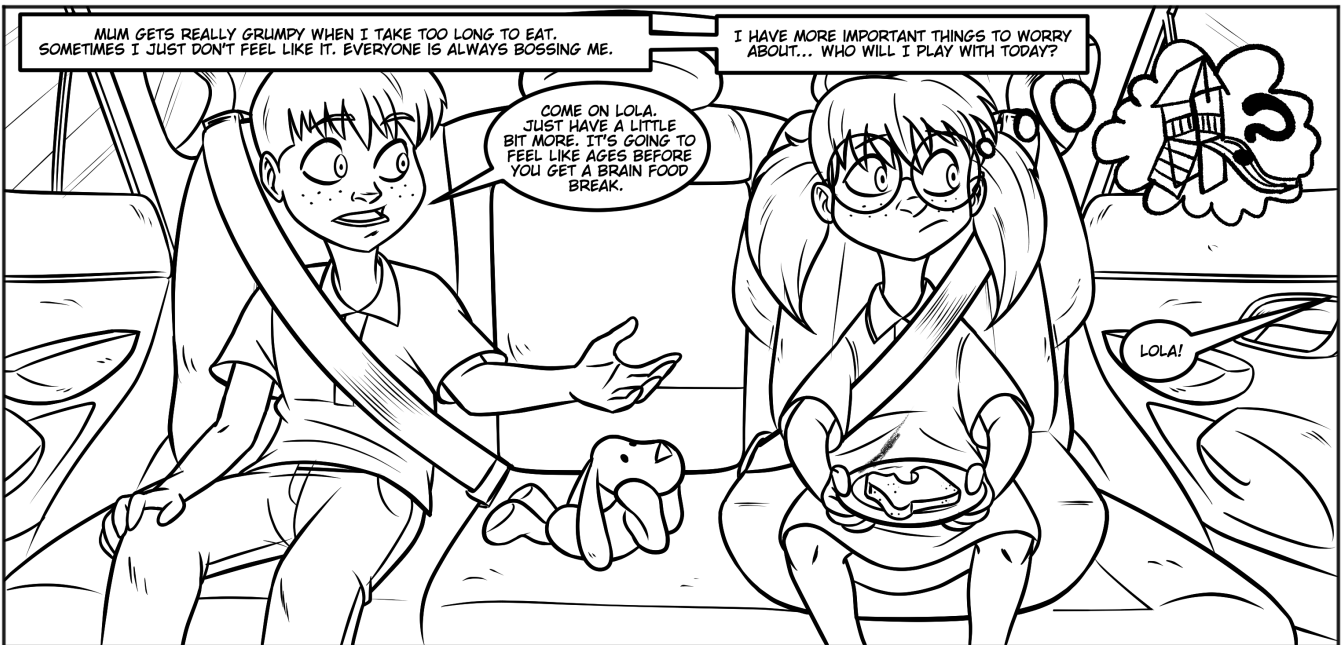
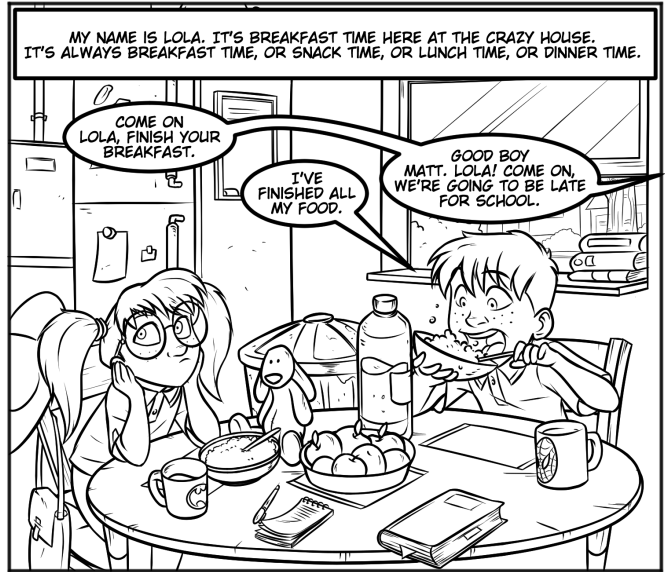
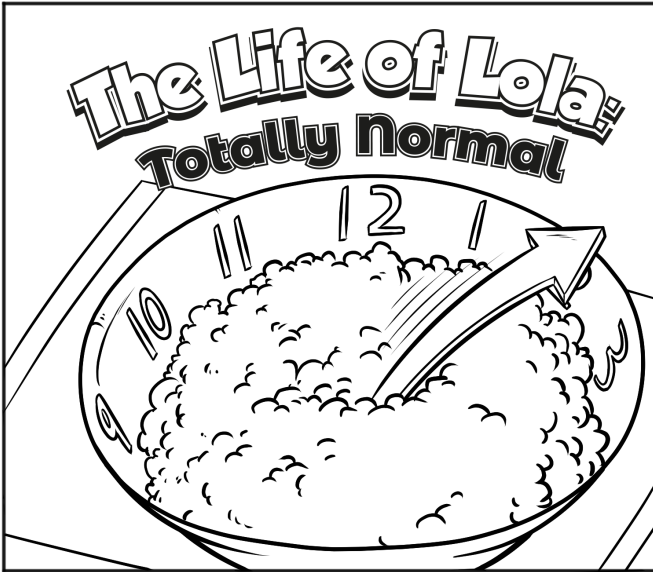
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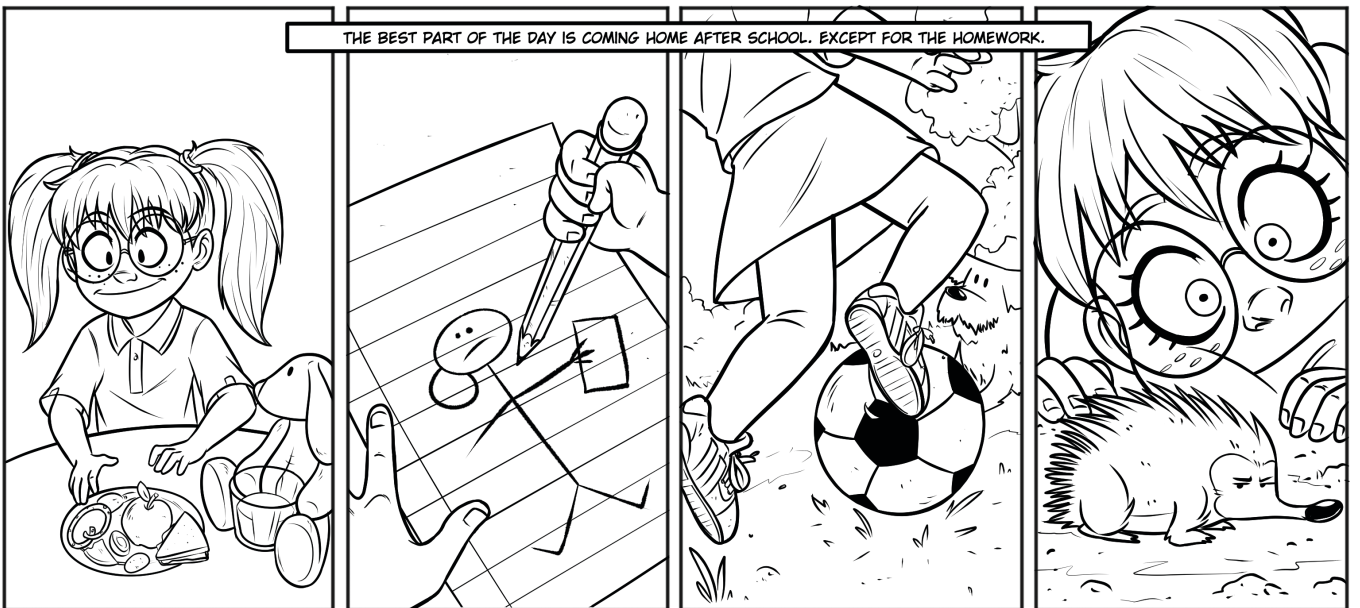
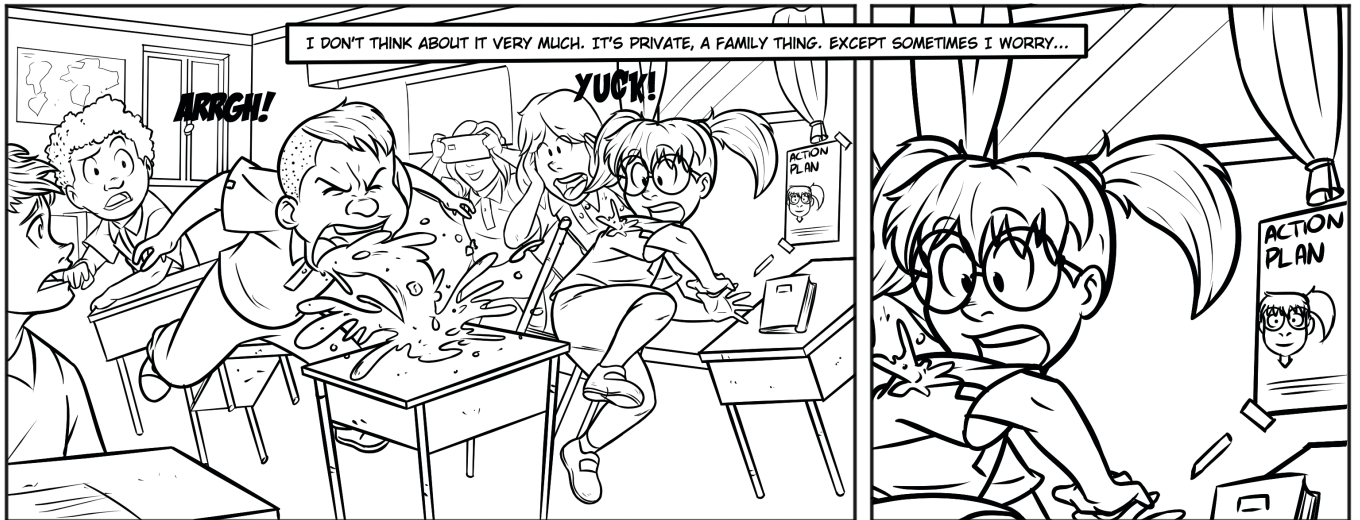
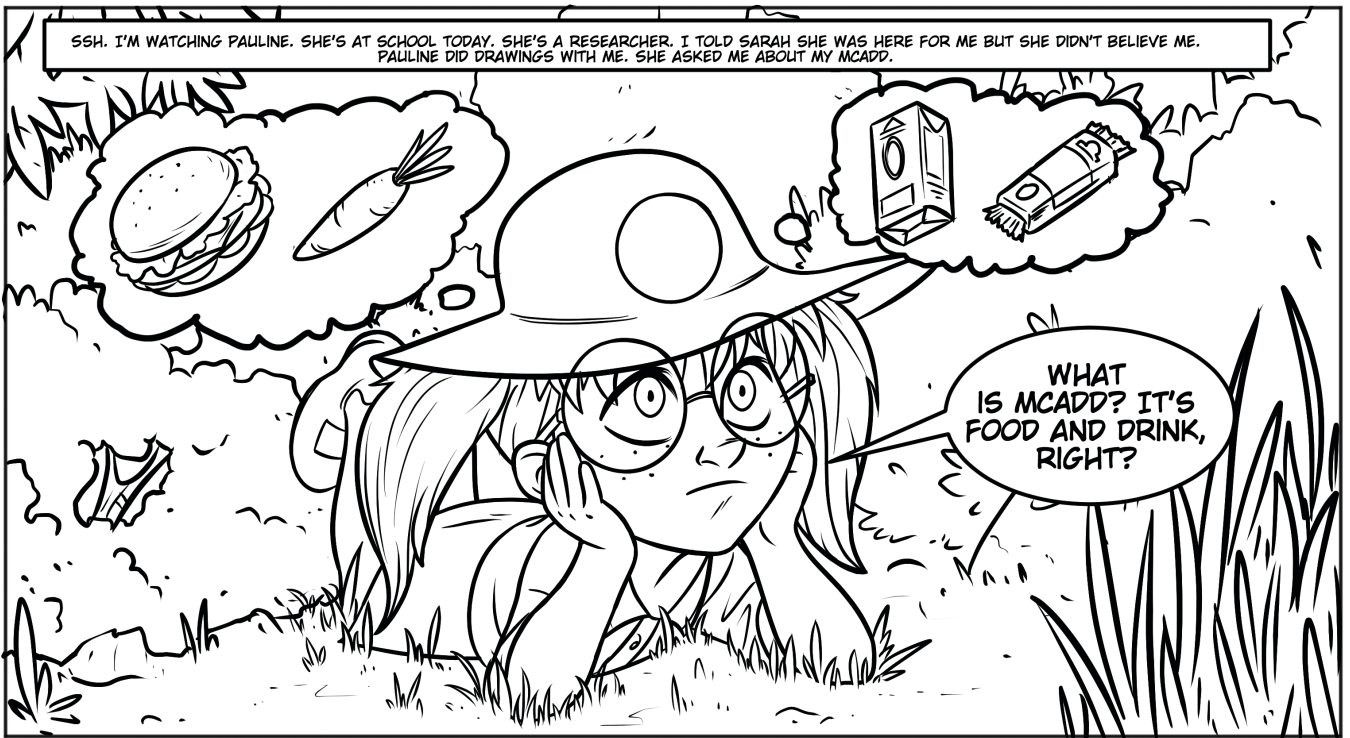
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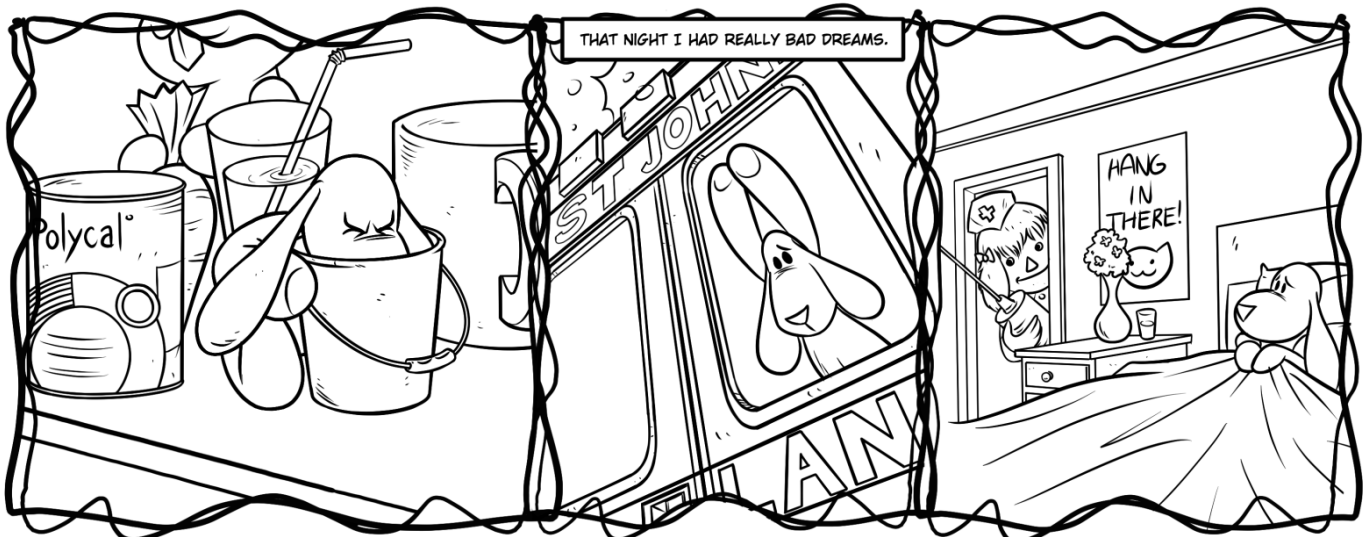
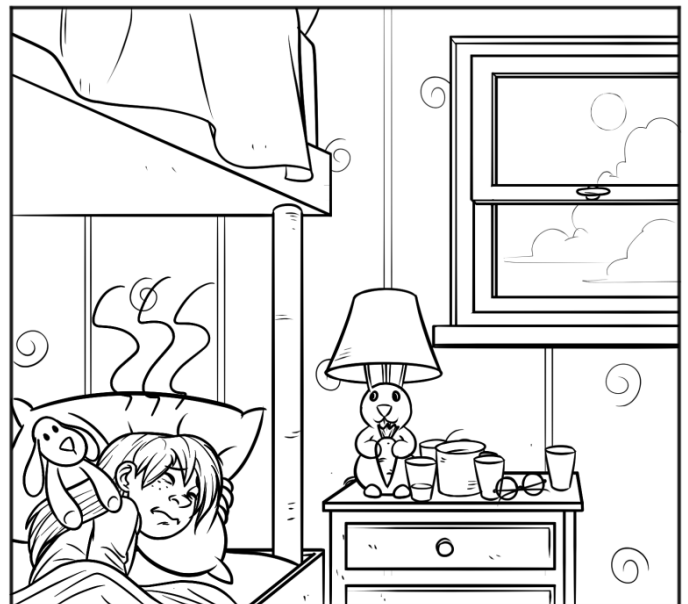
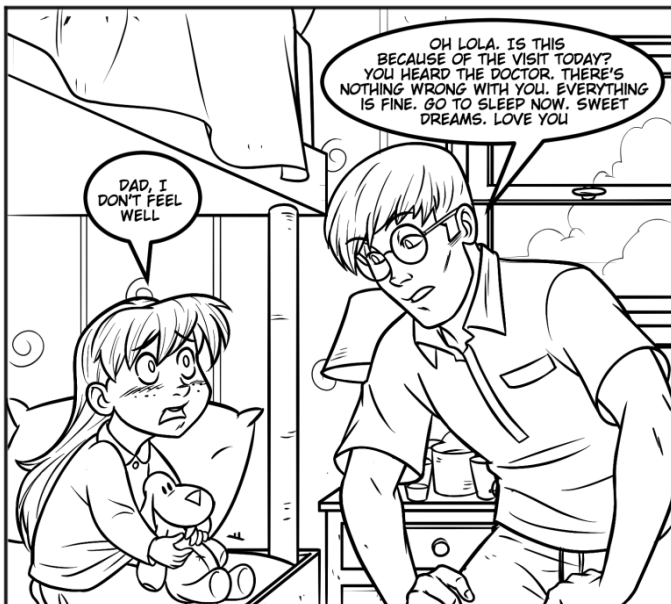
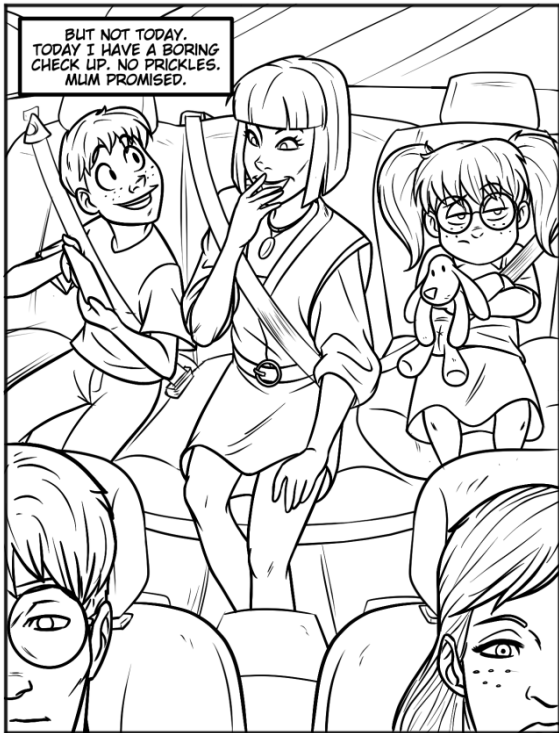
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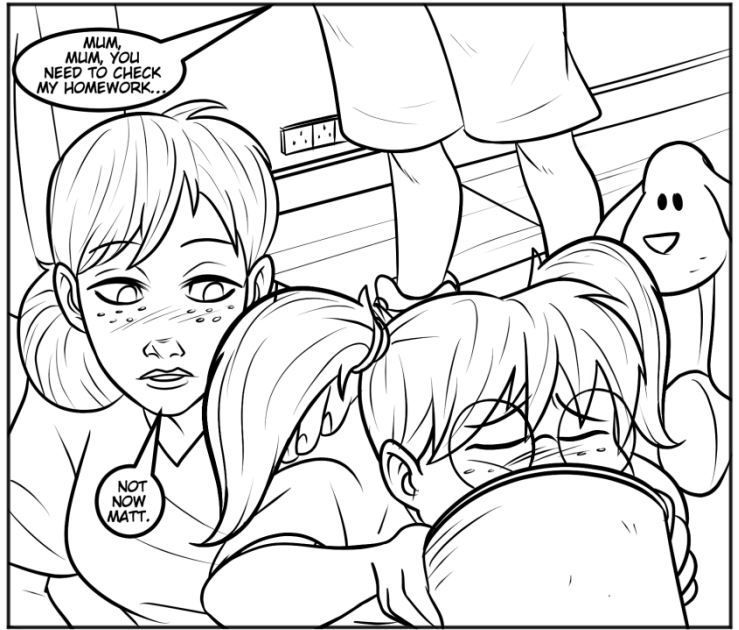
Written by Pauline Herbst

Pencils by William Calleja Ink by Daniele Sapuppo









Part I. A Sensory Journey

'Life of Lola' is a four-page comic, an ethnographic work of creative non-fiction, a series of simple black and white line drawn characters, their words and thoughts floating in balloons above their heads, their expressions and bodily positions sometimes in sharp contrast with those words. However, within these four flat pages I have distilled two years of fieldwork, six field journals, two diaries, a 77,218 word manuscript and the daily lived experience of 31 children and young people diagnosed with Medium-Chain Acyl CoA Dehydrogenase Deficiency (MCADD). A picture can tell a thousand words. A series of these can show an entire life. Such is the power of the comic.

There is a small but growing body of multidisciplinary work around the genre of graphic anthropology and medicine (Hamdy and Nye 2017) and its ability to analyse and communicate issues in illness, medicine, and disability and add to our understanding of 'health.' Al-Jawad (2015: 372-373) argues (in graphic form) that comics can be used as a research method due to their ability to 'unlock emotional responses to data,' promote reflective practice and 'offer a resistance to the medical mainstream.' McMullin (2016: 150) situates these 'as part of a medical imaginary in the era of biomedicalization.' As she states, graphic narratives illustrate the everyday. Ambitiously, a forthcoming graphic novel by Alex Pavlotski outlines what this form does for anthropology.

What can we learn about the social life of diagnosis through a graphic narrative of MCADD? The comic above does not explicitly tell the reader that MCADD is an inherited metabolic disorder in which a child is either missing the enzyme to metabolise fat, or that it is not working properly. It does show that children have to eat whether they like it or not, that they cannot rely on their fat stores to give their bodies energy, and that periods of fasting can be extremely dangerous and life threatening. The comic was developed in combination with other creative narratives to support a larger body of work; a nationwide New Zealand ethnography that sought to discover whether the diagnosis of a life threatening condition affected a child's developing sense of personhood (Herbst 2019). In this work, I examined the daily lived experience of the first generation of children to be diagnosed with medium-chain acyl-CoA dehydrogenase deficiency (MCADD). MCADD is an inborn error of metabolism that was included in the expanded newborn screening programme in New Zealand in 2006. Without screening, one in four undiagnosed babies could die but once diagnosed, children may never become symptomatic due to ongoing treatment, which is as simple – and as complicated – as eating regularly. Childhood illnesses that cause vomiting, high fever or loss of appetite necessitate hospitalisation until the child is well again.

I had always planned some sort of graphic and creative component of the manuscript, to explore Sherine Hamdy's question: "Might there be a space for a 'graphic medical anthropology' that could bring medical anthropological and bioethical insights into more public engagement" (Dedios et al. 2014: 2). I wanted this work to embody the daily lived experience, the lifeworlds of these children I was working with. I discovered it was tricky and slippery. The models I initially created seemed flat and inconsequential. This was a condition that affected

everything about a child, and yet nothing. It was a ghost, an elusive bogeyman that crept out from under the bed when children were sick, little and vulnerable and then crept back under, leaving rationales of ‘it’s ok’ and ‘it is easily managed’ and ‘at least it’s not something else’ in its trail.

Language has limitations and so I turned to the graphic. I wanted the reader to climb inside the body and mind of these children, to feel what they are feeling. It was only after a period of sitting with the data that I realised I needed to short-circuit a path to the sensory. I wanted to show the complexity of the impact of this condition on young people’s lives; the seething sibling rivalry, the discontent when one child feels their sibling is favoured and yet worried and guilty about that same sibling’s health. Children showed me how their imagination created potential futures, based on what they had heard will happen and the phenomenological experience of being inhabited by that illness – so much so that they are scared of telling their parents when they feel nauseous. I also wanted to express the complete banality of living with the diagnosis, how for some children at certain times, the condition simply doesn’t exist: it’s an inconvenience, an interruption to the things that are important in their worlds; playing, friendships, exploring. That these clinics are just ‘something that happens’ but at the same time also mark a child as something other. How, then, to communicate this to a range of readers: academic, clinical, and families?

My aims in creating the comic were to take the themes that had emerged from rigorous analysis and render them visible – for the sensory to engage the reader and also for non-academics to be able to engage with the research. I wanted to make visible a slippery concept I had developed called ‘shadow habitus’ (Herbst 2019); a concept I use in relation to chronic illness. Shadow habitus describes an enduring habitus that shapes a primary set of dispositions based on the prevention of illness exacerbation. This shadow habitus is developed during times of increased risk but remains even during times of apparent health. The comic was an attempt to visualise the concept. But what value did this graphic narrative form hold and what did its creation teach me about knowledge creation and ethnographic practice?

Part II. The trial of obscurantism

The comics’ main contribution is in terms of representation. I think and write with my senses; field journals include descriptions of fish decals in a hospital waiting room swimming towards a destination they’ll never reach; soundscapes of sobbing and the silences that are never truly still. As Csordas (1993), Narayan (2012) and Pink (2009) have all observed, we experience the research locale with our bodies and senses and this must be brought to our analysis and imparted to readers. I make a case for the use of graphic anthropology, more than a ‘one-to-one translation of ethnographic field notes [but] a method for seeing and communicating relationships in the field’ (McMullin 2018); a way of illustrating the everyday. The comic furthered the anthropological endeavour, making sense of what makes us human. I intend this as a critique on anthropological ways of writing culture, a critique spearheaded by Clifford and Marcus’ (1986) text that has been developed by writers such as Abu-Lughod (1993, 1999) and Behar

(1996). I draw on Stoller (2015), Wolf (1992) and Van Maanen (2011) to advocate for a more inclusive way of allowing our participants' voices to be heard, in particular those at risk of being muted through illness or age. Here I consider what Stoller refers to as:

... a 'mutually influencing dynamic relationship between ethnography and fiction', acknowledging that literary modes of writing, including fiction, enable anthropological scholars to uncover evidence and explore ideas about the human condition that are, 'for the most part, inadequately expressed in the discipline' (Stoller 2015 in Wiles 2018: 10).

As Gottlieb has stated, increasingly anthropologists acknowledge that it does not make intellectual sense to divorce affective considerations from our analyses when they are a key component of the experiences that form the bedrock of our understanding (Gottlieb 2016: 101). Additionally, opening our work to further accessibility is important towards further attempts to decolonize anthropology and make a stand against what Ellen Hertz (2016) rails against as obscurantism in academic writing. In this work I have used a composite character, Lola, to illustrate the socially constructed nature of illness, representing her diagnosis and daily lived experience and encounters with 'her' MCADD through her own words and actions in comic form.

Much like others who advanced this discussion post-Wolf (1992), I argue that preserving the mood and sensory aspects of the ethnographic encounter is vital to presenting an authentic, self-reflexive picture, and that this can be used to enhance the nuances of analysis. As Pigg (2018) notes in her commentary on the illness narrative canon:

They show important things about sickness and the quest for healing, but they don't ask the sorts of questions anthropologists ask about cultural common sense and structuring assumptions, let alone see the production of medical knowledge as a story in its own right.

It is the creation of this piece of graphic anthropology that illuminated sub-conscious and reflexive patterns of thinking valuable to the ethnographic endeavour.

Life of Lola illustrates a particular cultural and personal history through Lola, a composite character created from experiences observed and shared by the young participants in this study. It highlights how some of these children feel at specific points; frustrated by the power differentials at mealtimes yet using knowledge of their condition to test social parameters, concerned about their peer relations at school, ambiguous and agentive about and during their outpatient clinic appointments, and frightened when they do develop or contract a childhood illness as they believe this leads to hospitalisation. This is the end point, presented as an ethnographic work of creative non-fiction. In the following section I describe how this came about and what I learned about ethnography in the process.

Part III: 'Writing' graphic anthropology

The comic serves as a way of thinking with and through Bourdieu's concept of habitus. The comic illustrates what I have termed the *shadow habitus* – a concept I argue is particular to newborn screening for chronic genetic disorders. We see how Lola's diagnosis of MCADD has created a medicalised body in need of preventative treatment: she must eat, and eat well every day. The outpatient clinics and hospital admissions she has experienced help to construct the impression of a pathologised body. Despite being at primary school, the experiential, sensory knowledge she has of her preventative treatment in the first few years of life leads her to be fearful of hospitalisation, so that when she feels nauseous, she doesn't want to tell her parents in case she is hospitalised. The comic visually shows how the body of Lola, diagnosed with the potential for illness, has as much capacity to transform her young life as illness itself. A shadow habitus remains even after moving through this phase of early prevention.

When we write ethnography, we need to think about how we are writing it and what we are portraying. But often, this is taken for granted. After years of training and immersion in ethnographic practice, the act of writing becomes reflexive and habitual. Trying to visualise what I was trying to write and expressing these concepts in the form of a script for an artist revealed hidden layers that I found valuable: should 'Lola' be male or female and why? What age should she be? What should she look like? Cultural differences in the way we portray our teachers, doctors, clinics, schools and school children were revealed in early storyboards as the artists presented and queried representation. There is a panel where I insert myself after much reflexive thought, based on a teacher telling me: 'he is aware of your observation, he told me "she's here for me you know."' Another panel illustrates the knotty conundrums at the heart of ethnography and one that the biomedical specialists I work with wanted to know: how do you know that you aren't affecting these children, that they wouldn't even think about MCADD and its effect on them if you weren't there to prompt those questions? Children wanted me to provide answers to the questions I was asking them, while searching for their own solution to the query: 'what is MCADD?' They, of course, have their own answers. Parents thought I could provide a succinct answer but as my research uncovered (and anthropologists know) the answer is fluid and relational. The answer Lola gives in the comic was just one of the themes that came out of the ethnography: MCADD is, in many instances, 'food and drink.'

The script was thus developed after extensive analysis and coding of field notes and annotated with detailed art notes to enable an illustrator to draw the images:

Panel 4b: Inciting incident

CLOSE UP OF LOLA OR JUST PART OF HER FACE AND SHOULDER WITH A BIT OF VOMIT ON IT. BEHIND HER AN IMAGE OF AN 'ACTION PLAN' ABOUT LOLA'S CONDITION (SENT AS A SEPARATE FILE) AND WHAT NEEDS TO BE DONE.

STRIP 3: [Home environment – happy. A series of interconnected panels]

Caption: The best part of the day is coming home after school. Except for the homework.

Panel 5a:

LOLA AT THE TABLE WITH A PLATE OF SNACKS, FRUIT (SOMETHING EASILY IDENTIFIABLE LIKE BANANA, APPLE, MANDARIN SEGMENTS), A BISCUIT, SOME PRETZELS OR TINY TRIANGLE SANDWICH OR TWO...

Panel 7:

AERIAL VIEW OF A CRAMPED ROOM WITH A DOCTOR AT THE TABLE, 4 NURSES, A BED, 2 CHAIRS WITH PARENTS. [I'll send you a sketch of room object placement from my field notes].

This comic was a collaborative rather than a linear process. The artists and I worked with the material back and forth, enmeshing the visual storyboard and the developing script with my explanations of anthropological concepts, the lived experience of the condition and what I was trying to portray in each panel with their skills and experience of working in the comic form. The creation of the comic became a tool for thinking critically about what this ethnography was doing and why, and how it could be read in relation to other works of graphic anthropology. It touches on the key themes that the children brought up in discussions about MCADD and highlights the ambiguities inherent in discussing an invisible condition that even clinicians do not fully understand.

To conclude, the comic revealed the shifting and elusive nature of the porous boundaries between illness, health and dis-ease, circling through a variety of situated perspectives and spaces crucial to understanding the lived experience of MCADD. Comics have much to offer medical anthropology including complex theoretical concepts simplified in visual form for non-specialist readers and the lived experience of those diagnosed with a chronic condition illustrated for clinicians and others who are used to a particular way of encasing and seeing patients.

What do comics then do for ethnography? They are a tool, a final product and a method. If writing is a way of thinking, then laying out a storyboard is a visual way of filtering what you are seeing and doing during participant observation. What does this do for the discipline broadly? It makes it accessible. It protects it. It opens rather than closes it. It opens new ways of thinking to ourselves, the ethnographers. I used this short comic to illustrate how what I have called the 'shadow habitus' can develop and endure well after a child has grown enough to be out of a clinically defined dangerous period. A picture can tell a thousand words. A series of these can show an entire life. When a reader engages with the work and entangles their own lives with the other – that is the power of graphic anthropology.

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