Title

Coming of Age in High-Tech Medicine: Heart Transplantation, Collaborative Visual Storytelling and Transformational Pedagogy

Author

Tanio, Nadine

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Coming of Age in High-Tech Medicine:
Heart Transplantation, Collaborative Visual Storytelling
and Transformational Pedagogy

A dissertation submitted in partial satisfaction of the

requirements for the degree Doctor of Philosophy

in Education

by

Nadine Tanio

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ABSTRACT OF THE DISSERTATION

Coming of Age in High-Tech Medicine:

Heart Transplantation, Collaborative Visual Storytelling

and Transformational Pedagogy

by

Nadine Tanio

Doctor of Philosophy in Education

University of California, Los Angeles, 2020

Professor Douglas M. Kellner, Co-Chair

Professor Federica Raia, Co-Chair

This dissertation explores how young heart transplant patients envision, articulate and navigate their transition from pediatric to adult medical care. In other words, it focuses on how young people learn to care for themselves in the context of modern medicine. A generation ago few children diagnosed with severe disability survived to adulthood.[1] Today, the average pediatric post-transplant heart patient survives 12-18 years.[2] Nevertheless, transition is marked by a just as young people gain responsibility for their care.[3]

[1] Blum et al., "Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions."

[2] Hollander et al., "Quality of Life and Metrics of Achievement in Long-Term Adult Survivors of Pediatric Heart Transplant"; Kirk and et al., "The Registry of the International Society for Heart and Lung Transplantation."

[3] Foster, "Heightened Graft Failure Risk during Emerging Adulthood and Transition to Adult Care"; Dharnidharka and et.al., "Across All Solid Organs, Adolescent Age Recipients Have Worse Transplant Organ Survival than Younger Age Children."

Arising from ongoing participatory research on advanced heart failure (AdHF) medicine with medical practitioners, patients and family caregivers,[4] this qualitative study examines visual storytelling as transformational pedagogy. Using youth participatory action research (YPAR),[5] situated between critical media literacy production[6] and pedagogies of transformational resistance,[7] this dissertation is an ethnography of a collaborative video storytelling project with two young women who each received multiple heart transplants as children and are coming of age in the context of high-tech medicine. By means of visual storytelling, I sought to support young women in transition and discover: a) what stories they define as important to share; b) what narratives get chosen, discarded and revised, c) how narrative decisions are made within collaborative practices and, d) how knowledge about living within biotechnological culture is constructed.

The dissertation is organized in three parts. The first part provides the context for storytelling as a means to examine transition in pediatric transplant medicine. The second part is an ethnography of learning that discusses collaborative research through three stages of video production. The third and final part positions collaborative storytelling as a form of transformational pedagogy and highlights youth expertise within the knowledge ecology[8] of medical care.

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[4] Raia and Deng, *Relational Medicine*.

[5] Cammarota and Fine, *Revolutionizing Education*; Caraballo et al., "YPAR and Critical Epistemologies: Rethinking Education Research"; Tuck, "Theorizing Back: An Approach to Participatory Policy Analysis."

[6] Kellner and Share, "Critical Media Literacy, Democracy, and the Reconstruction of Education"; Hammer, "Critical Media Literacy as Engaged Pedagogy."

[7] Cammarota, "Youth Participatory Action Research: A Pedagogy of Transformational Resistance for Critical Youth Studies"; Solorzano and Bernal, "Examining Transformational Resistance Through a Critical Race and Latcrit Theory Framework."

[8] Sofoulis et al., "Coming to Terms with Knowledge Brokering and Translation. A Background Paper."

Research findings reveal the tensions associated with coming of age in the interstices of disability/difference[9] while living with existential uncertainty and the rituals of care that structure daily life. Through educational research I seek to build narratives of positionality, practice and pedagogy that create communities for learning and living within the transitory spaces of modern medicine.

Keywords: heart transplantation, visual storytelling, transition, care, critical media literacy, critical disability studies (CDS), youth participatory research (YPAR), ethnography, transformational pedagogy, feminist science studies

[9] Erevelles, "Educating Unruly Bodies"; Shildrick, "Critical Disability Studies."

The dissertation of Nadine Tanio is approved.

Marjorie Harness Goodwin

Ananda Maria Marin

Sharon J. Traweek

Douglas M. Kellner, Committee Co-Chair

Federica Raia, Committee Co-Chair

University of California, Los Angeles

2020

DEDICATION

For my son Isaac Ebesu, and my partner Glen Ebesu.

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I wish to acknowledge the work of my committee members in supporting this dissertation. Douglas Kellner enabled my return to UCLA and opened a space for me to pursue lingering questions I thought had been long abandoned. Federica Raia introduced me to the study of advanced heart failure through the lens of relational medicine. She welcomed me into her study team and supported this work throughout its long development. Candy Goodwin taught me to pay attention to the choreography of language. She and her husband, the late Chuck Goodwin, generously shared their insight and love of research. Ananda Marin sharpened my analysis and provided encouragement and care at critical times during this dissertation. I first met Sharon Traweek when I was a graduate student in the History of Science. Years later, as a returning student, I was thrilled when she agreed to serve on my committee. I am deeply indebted to her profound wisdom and mentorship.

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[10] pseudonyms

Teachers have been crucial sources of inspiration and support throughout my life. I wish to pay my respects to Miss Anderson and Mrs Chmelar, teachers who taught a young girl to read as well as to be curious and brave.

I met Mario Biagioli and Carlo Ginzburg at a critical time in my undergraduate studies. They were the first professors who recognized and nurtured a nascent scholar. I was lucky to meet Sandra Harding when I first started graduate school. Time and again I have solicited her advice and she has been unfailingly generous in her support and encouragement. Stefania Pandolfo, my mentor at UC Berkeley, taught me lifelong lessons about the beauty, poetry and resilience to be found in scholarly pursuits. As I was writing my dissertation I had the good fortune to meet Kim and Mike Fortun who generously welcomed me into their own collaborative practices. The lessons I learned from all my teachers suffuse this work. Mistakes and mis-steps are mine.

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VITA

Education

University of California, Los Angeles	Ph.D. candidate, Education
University of California, Berkeley	M.A., Cultural Anthropology
University of California, Los Angeles	Graduate Studies, History of Science
	B.A., Double Major, History and Psychology

Awards and Fellowships

National Academy of Education	2018 NAED/Spencer Dissertation Fellow
University of California, Los Angeles	2014-2017; 2019 University Fellowship

Publications

Kawasaki, J., Anderson-Levitt, K.M., Nenadal, L., Tanio, N., Pham, J., Diera, C., and Francois, A. "From Theory to Practice: How Pre-service Science Teachers Learn to Become Social Justice Educators," in *ICLS 2018 Proceedings: 17th International Conference of the Learning Sciences*.

Tanio, N. "Photographier Bali: la vision, la réflexivité et le réel ethnographique," *Xoana: Images et Sciences Sociales*, pp: 27-47.

Tanio, N., "Gendering the History of Science," *Nuncius* 6, no. 2, pp. 295-305.

Films

Tanio, N., Malik, S., Ebesu, G. "Sarah" (2019)

Tanio, N., Ostrand, J., Ebesu, G. "Jessica" (2019)

Conference Presentations

Tanio, N., "Medication as Curriculum: Listening to the Spaces in-Between" (accepted paper), American Educational Research Association, San Francisco, CA 2020.

Tanio, N., "Coming of Age in High-Tech Medicine: Knowledge Ecologies, Collaborative Storytelling, and Heart Transplantation." Presentation in Feminist Technoscience by Other Means: Reconfiguring Research Practices for World-Making Beyond the Academy, 4S, Society for Social Studies of Science, New Orleans, LA.

Tanio, N. and Malik, S., "Collaborative Research in Action: Critical Media Production, Heart Transplantation, and the Transformative Possibilities of Storytelling." Poster Presentation, Nadine Tanio and Sarah Malik, American Anthropological Association/Council on Education and Anthropology, San Jose, CA, 2018

Tanio, N., "The Stories We Tell: Growing Up in High-tech Medicine," STS Making and Doing Presentation, 4S, Society for Social Studies of Science, Sydney, Australia, 2018

Tanio, N., "Pedagogy in Practice: Teaching and Learning in a Cardiac Care Unit," Poster Presentation, AAA/CAE, Washington, DC, 2017

Anderson-Levitt, K., Diera,C., Nenadal, L., Pham, J and Tanio, N., "From Theory to Practice: How Apprentice Teachers Learn to Become Social Justice Educators," Working Group Roundtable, AERA, San Antonio, TX, 2017

Nenadal, L., Tanio, N., Pham, J., and Diera, C., "The multiple meanings of social justice in an urban residency teacher education program", AACTE, Tampa, FL, 2016

Diera, C., Nenadal, L., Pham, J. and Tanio, N., "The Multiple Meanings of Social Justice in an Urban Residency Teacher Education Program." Conversational Roundtable, Research and Inquiry Conference, UCLA, 2016

Tanio, N., "The Exquisite Corpse: Learning Embodied in a Collaborative Printmaking Workshop." Poster Presentation. The 22nd Annual Conference on Language, Interaction, and Culture, UCLA, 2016

Tanio, N., "Homo Ludens and the Poetics of Play." Poster Presentation. Research and Inquiry Conference, UCLA, 2015

Tanio, N., "Children's voices and agency in math learning." Presentation. Research and Inquiry Conference, UCLA, 2015

Tanio, N., "Children's voices and agency in math learning." New Scholars Poster Session. AAA/CAE, Denver, CO, 2015

Invited Presentations

American Educational Research Association, Toronto, Canada, 2019
Poster Presentation in Promising Scholarship in Education Research: Dissertation in Education Research: Dissertation Fellows and Their Research Session,
Tanio, N., "Collaborative Research in Action: Heart Transplantation, Visual Storytelling and an Ethics of Care"

National Academy of Education/Spencer 2019 Spring Fellows Retreat

National Academy of Education/Spencer poster session, 2018 Fall Fellows Retreat and Annual Meeting

UCLA, Gender Studies 187, Senior Research Seminar on Oral Life Histories, 2019

UCLA, School of Education 187, Special Topics in Education

Professional Experience

- Teaching Fellow, Gender Studies/History M180B; Gender Studies 187
- Graduate Student Researcher, GSEIS
- Teaching Assistant, Education187
- Graduate Student Researcher, International Studies,
- Graduate Student Researcher, Cardiology Division, David Geffen School of Medicine, UCLA.
- Producer, *Through the Wormhole with Morgan Freeman*, Science Channel. Non-fiction series Season 2 and 3
- Co-Producer, Associate Producer, *Through the Wormhole with Morgan Freeman*, Science Channel. Non-fiction series Seasons 1
- Associate Producer, Field Producer, *Muhammad: Legacy of a Prophet.* PBS feature documentary. Kikim Media and Unity Productions Foundation.

Professional Affiliations

- American Educational Research Association (AERA)
- American Anthropological Association (AAA)
    - Council on Education and Anthropology (CAE)
    - Anthropology of Children and Youth Interest Group ACYIG
- European Association for the Study of Science and Technology (EASST)
- Society for Disability Studies (SDS)
- Society for Social Studies of Science (4S)

Part One

Chapter 1- Sketching the Terrain

"I prefer to regard transition as a process, a becoming"

—Victor Turner[11]

Introduction

Transition, the move from pediatric to the adult healthcare system, is an emergent topic in transplant medicine as more pediatric heart transplant patients are living to adulthood.[12] Organ transplantation itself, a procedure that could only emerge within a biotechnological culture, transforms our understanding of the limits and possibilities of the body and what it means to be human. In this study, transition is a discrete event—the move from pediatric to adult healthcare—and a more open, continuous process: the transition from adolescence to adulthood. In this way it is similar to Arnold van Gennep and Victor Turner's discussion and elaboration of *rites of passage*, where transition is a 'state' of being, but it is also a *becoming*.[13] These works of classic anthropology position liminality as a threshold, a temporary passage between two stable states. More recent scholarship in the social sciences questions the very idea of stability as a state of being, of culture, or of knowing.[14] Informed by these discussions,

[11] Turner, *The Forest of Symbols*, 94.

[12] Blum et al., "Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions"; Stam et al., "Young Adult Patients with a History of Pediatric Disease"; Reardon et al., "Correlation Between Lipid Levels and Cardiovascular Events in Heart Transplant Recipients."

[13] Gennep, *The Rites of Passage*; Turner, *The Forest of Symbols*.

[14] Key texts for me include: Haraway, "A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980s"; Lugones and Spelman, "Have We Got a Theory for You! Feminist Theory, Cultural Imperialism and the Demand for 'the Woman's Voice'"; Sandoval, *Methodology of the Oppressed*; Crenshaw, "Identity Politics, and Violence Against Women of Color."

this study resides within the betwixt and between, uncomfortably de-centered, resisting stability. In this way it is also a work of critique, learning from critical theory[15] that cultures of learning and care are particular cultural ecosystems bounded in time and space. Judith Butler describes the work of critique as:

> [O]pening up the possibility of questioning what our assumptions are and somehow encouraging us to live in the anxiety of that questioning without closing it down too quickly. Of course, it's not for the sake of anxiety that one should do it...but because anxiety accompanies something like the witnessing of new possibilities.[16]

This dissertation seeks to understand how young heart transplant patients envision, articulate and navigate their transition from pediatric to adult medical care. In other words, it focuses on how young people learn to care for themselves within the context of high-tech modern medicine through an educational, participatory action research of collaborative video storytelling. My choice to focus on the betwixt and between is my contribution to critique as a research trajectory, not simply to bear witness to, but to actively seek to co-create new possibilities for understanding and thinking about ecologies of care afforded through the collaborative crafting and sharing of young people's stories of transition.

Setting and context

[15] There are multiple traditions which inform critical educational practice, these traditions include critical disability studies (Shildrick, "Critical Disability Studies"; Erevelles, "Educating Unruly Bodies"; Siebers, *Disability Theory*.), critical ethnography (Traweek, *Beamtimes and Lifetimes*; Goodyear-Ka'ōpua, *The Seeds We Planted*; Simon and Dippo, "On Critical Ethnographic Work.") and critical media studies (Kellner and Share, "Critical Media Literacy, Democracy, and the Reconstruction of Education"; Share, *Media Literacy Is Elementary*; Luke, "Media Literacy and Cultural Studies.").

[16] Quoted in Shildrick, "Critical Disability Studies," 31. This is an unusual case of a tertiary source for Shildrick is quoting from an interview that is quoted in Salih and Butler (2004:331). For the original see: Olson, Worsham, and Giroux, *Politics of Possibility*, 14. Nevertheless, Shildrick's editing of Butler's longer answer warrants this tertiary use.

The context of this study is the contemporary United States[17] where organ transplantation for end-stage organ failure is established practice.[18] Transition in transplant medicine remains a highly specialized experience. Access to high-tech medical care in moments of crisis, and to specialized continuity of care at all times, is the purview of a privileged few. Nevertheless, it is my assertion that even the experiences of a small community of young heart transplant recipients sheds light on transition as a process of becoming in the new spaces opened by high-tech modern medicine.[19] In this way, this study is a "telling case,"[20] an opportunity to examine the ways in which organ transplantation is not an endpoint, a solution of last resort, rather heart transplantation is the beginning of hybrid ways of being and becoming. For young people coming of age in the *aftermath* of heart transplantation, where living with chronic and complex medical conditions are "normal" daily activities, their experiences of inhabiting the geographies opened up by high-tech modern medicine provide insight to a shared cultural ecosystem and helps us make sense of this contemporary moment.

This study is situated within Federica Raia's ongoing participatory team research project examining Advanced Heart Failure (AdHF) medical encounters between adult and adolescent patients, their healthcare team and family caregivers.[21] Raia's study initially focused on adult

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[17] For a study examining organ transplant in a different cultural context see Lock, *Twice Dead: Organ Transplants and the Reinvention of Death*.

[18] Transplantation is often referred to as the "gold standard" to signal the quintessential treatment option available for end-stage organ failure. See, Vistarini et al., "Changes in Patient Characteristics Following Cardiac Transplantation"; Kobashigawa, "The Search for a Gold Standard to Detect Rejection in Heart Transplant Patients"; Lee and Tang, "Renal Transplantation"; "Heart Transplant > Condition at Yale Medicine."

[19] Raia and Deng, *Relational Medicine*; Mauthner, "The New Normal"; Shildrick, "Disrupting Hybrid Bodies."

[20] Mitchell, "Case Studies"; Andrews, "Is the 'Telling Case' a Methodological Myth?"

[21] Raia and Deng, *Relational Medicine*; Raia and Smith, "Practitioner's Noticing and Know-How in Multi-Activity Space of Patient Care and Teaching and Learning"; Raia, "Identity, Tools and Existential Spaces"; Raia, "Breakdown and Care: Navigating the Process of Being and Becoming in High-Tech Modern Medicine."

AdHF patients and developed in partnership with Dr. Mario Deng, a renowned clinician and biomedical researcher on heart failure and heart transplantation, a new model for modern clinical practice called *Relational Medicine* in which the practice of caring for patients is understood as a "Relational*Act*".[22] Raia and Deng's work was instrumental in shaping this study.

A key standpoint in Raia's work is an examination of learning as a process of being and becoming—becoming a certain kind of person, a certain kind of practitioner.[23] More specifically, education is understood within the theoretical lens of fundamental ontology where heart failure is examined as a process of breakdown that impacts the heart and also, always, an already embodied sense of self. [24] Breakdown inaugurates an existential crisis where life, in the aftermath of a heart transplantation and/or living with a machine-assisted device, necessitates a process of learning and becoming that reverberates across all aspects of being, including an individual's sense of themselves and their self/body integration. The philosopher Jean-Luc Nancy who underwent a heart transplant in the 1990s captured the complexity of this existential crisis in an essay, "The Intruder." He wrote:

> If my own heart was failing me, to what degree was it "mine," my "own" organ? Was it even an organ? For some years I had already felt a fluttering, some breaks in the rhythm, really not much of anything… not an organ, not the dark red muscular mass loaded with tubes that I now had to suddenly imagine…. It became strange to me, intruding by defection: almost by rejection, if not by

[22] *Relational Medicine*, 136–39.

[23] Raia, "Course Syllabus: Learning as Becoming."

[24] Raia, "The Temporality of Becoming."

> dejection. I had this heart at the tip of my tongue, like improper food. Rather like heartburn, but gently. A gentle sliding separated me from myself.[25]

Nancy's description of slippage, of a separation of "me from myself," that precipitates his own heart transplant exposes the disaggregation of his sense of self. Although Nancy describes this as a slow process, patients may also experience heart failure as a sudden, acute event where, in extreme cases, patients can awake from surgery and discover themselves with a grafted heart beating inside them and/or attached and dependent on machines whose visual and auditory conspicuousness serve as constant reminders that this is one's bridge to life. The work of Raia and Deng reveals how living, in the aftermath of an organ transplant, can throw an individual into a hitherto unknown hybrid space of existence located both inside and outside of one's body. This existential crisis initiates a process of learning—of being and becoming—that for the patient is a question of fundamental ontology, and for the physicians taking care of them and guiding them through this experience of dissimilitude is understood as a question of relational ontology.[26]

In the Spring of 2016, I joined Raia's ongoing team study just as it was expanding to examine pediatric and transitional transplant practices at the behest of patient co-researchers and practitioners. I was interested in how young people, whose emergent sense of self may not be as developed, or exteriorized or unified, may have a different perspective on their experience of heart failure and organ transplantation. Nancy's narrative of heart failure starts from a perspective of ownership. Prior to heart failure, *me*, *myself*, *my organ* exist as a unified self within Nancy. Subsequently, heart failure reveals the heart as a component part of a whole (body, self, identity), which is slowly slipping into dissociated parts. Nancy's description and

[25] Nancy and Rand, *Corpus*, 162–63.

[26] Raia and Deng, *Relational Medicine*; Raia, "The Temporality of Becoming."

self-reflection is both moving and insightful. It is also written from an adult's perspective. In coming to this work, the concept of breakdown seemed less apt when describing young people, for it presumes an already narrativized structure, a "before" and "after" in terms of identity, punctuated by heart failure.

As a doctoral student in education, I was interested in how young people made sense of these complexities, of how they engaged in knowledge production about living with a heart transplant especially within relations of power vis-à-vis adults and the institutions—like schools, families, hospitals—that structure their lives. I began ethnographic fieldwork in a pediatric post-transplant clinic and in specialized transition clinics while learning more about the history of heart transplants.

The emergence of transition: a problem in pediatric heart transplant (pHTx) care

The first heart transplant (HTx) was performed in South Africa in 1967 by Dr. Christiaan Barnard. Three days later, the first pediatric heart transplant (PHTx) was performed.[27] Although both patients survived these surgeries for only a few days, their procedures inaugurated a new model of high-tech medicine as a collaboration between medicine and scientific innovation.[28] Between 1967 and 2013 over 11,000 PHTx surgeries were performed.[29] Since 2013 between 500-600 PHTx surgeries are performed worldwide annually, a relatively stable number resulting from the scarcity of donor hearts.[30] In the five decades since 1967, progress in high-tech medicine has resulted in longer life-expectancy.[31] A generation ago, few children diagnosed with

[27] Zangwill, "Five Decades of Pediatric Heart Transplantation: Challenges Overcome, Challenges Remaining."

[28] Zangwill.

[29] Dipchand et al., "The Registry of the International Society for Heart and Lung Transplantation."

[30] Dipchand et al.

[31] Dipchand et al.

severe illnesses or disabilities, survived to 21 years of age.[32] Today, the average pediatric post-transplant survival is between 12-18 years.[33] As a result, many children who have received a heart transplant today will survive into adulthood. This success carries with it a set of challenges for pediatric cardiologists and adult AdHF specialists alike. As more pediatric patients survive, a more expansive practice of medical care has emerged shifting from a narrowly focused practice on heart failure to a practice that focuses on "building capacity of the young person to self-manage his or her condition within the context of broader life goals."[34] In terms of transitioning to adult providers, the medical profession has defined the goal of transition as providing "uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive" medical care.[35] Yet even as transition emerges as a key medical topic, one indication of the challenges facing the healthcare system is seen in the statistics, that although more adults with congenital heart disease (CHD) are living in the U.S. than children—1.4 million adults to 1 million children[36]—there are only 196 board-certified Adult Congenital Heart Disease specialists[37] as compared to the nearly 2500 pediatric cardiologists.[38] Once transitioned, patients and their families must then build relationships of care with different healthcare professionals in practices targeted for adult transplant populations. Patients and their families move from

[32] Blum et al., "Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions."

[33] Hollander et al., "Quality of Life and Metrics of Achievement in Long-Term Adult Survivors of Pediatric Heart Transplant"; Kirk and et al., "The Registry of the International Society for Heart and Lung Transplantation."

[34] Yates, *Keeping Connected*.

[35] Blum et al., "Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions."

[36] Gilboa et al., "Congenital Heart Defects in the United States."

[37] The ABMS only approved Adult Congenital Heart Disease as a board certified specialty in 2012, and issued its first certification in 2015, yet another signal that survivorship is a relatively new concern.

[38] ABMS, "ABMS Board Certification Report: 2015-2016."

pediatric wellness clinics—which include coordinated visits with pediatric cardiologists, nurse coordinators, social workers, child development specialists, psychologists, dieticians and dentists—to adult cardiac care without the additional specialized team support.

The complexity of transition as a nexus point may be best illustrated by this example. In an article about the current state of pediatric heart transplantation published in Medscape, an online resource intended for clinicians, Matthew Bock wrote, "survival in excess of 20 years after pediatric heart transplantation has been achieved." [39] He is justly celebrating 20 year survivability as a medical achievement. Yet, there is now a small cohort of transplant recipients who are moving past 20 year survivability. These young people inhabit a space and time hitherto unknown and unexperienced. For these young people, and the medical professionals who care for them, transition is a new and complex frontier. It is also, I argue, a space for teaching and learning that transcends a narrow paradigm of education as schooling.[40]

Growing up is a time of increased risk[41] for adolescents and young adults everywhere,[42] but for young people with heart transplants the journey to adulthood is particularly perilous. For heart transplant recipients the transition period can be experienced as a disruption in their life as well as a disruption in the continuity of their medical care. It marks a change in legal status

[39] "Pediatric Heart Transplantation."

[40] Lomawaima and McCarty, *To Remain an Indian*, 21; Levinson and Pollock, *A Companion to the Anthropology of Education*.

[41] In education, Ladson-Billings provides a trenchant critique of "at-risk" language as a means to further marginalize, sort, and categorize children, "From the Achievement Gap to the Education Debt: Understanding Achievement in U.S. Schools." I am uncertain if her critique is applicable to medical contexts of care especially in acute cases but I am cautious of the unreflective use of "at-risk" to describe all young people with chronic conditions. Nevertheless the medical literature on transition for adolescents and young adults with organ transplants is rife with this language and because I am trying to provide a glimpse at the medical context of transition amongst PHTx patients, I will use this language in this section.

[42] Bethany Foster notes that young men (15-24 years old) across the general population have death rates three times higher than same-age females and approximately six times higher than boys 5-9 years old, "Heightened Graft Failure Risk during Emerging Adulthood and Transition to Adult Care."

from childhood to adulthood with important consequences to the process of decision-making and management of one's own care that can lead to difficult and painful changes in roles and responsibilities for family caregivers. For heart transplant patients it also represents a "high-risk age window" when adolescents and young adults face worse transplant organ survival than younger children despite having better initial survival rates across all major organ transplants.[43] Although there is some speculation about the causes for this increased risk, the main belief is that increased mortality is tied to issues of non-adherence (non-compliance) as young people transition to adulthood and become responsible for their own care.[44]

In order to close the high-risk window, increase adherence, and support young people as they learn to care for themselves, newly formed "transition clinics" have been created to address specific challenges that adolescent and young adults face in transitioning to adult care. Transition clinics seek to facilitate the "hand-off"[45] between pediatric and adult providers sometimes through jointly staffed clinics[46] or through specialized clinical visits that include tours of the adult facilities and introductions to the adult healthcare team. This is the medical context in which this current study is situated.

From a medical context to an educational context of transition

Frederick Erickson calls qualitative research a form of deliberative inquiry—"one enters a setting with a particular purpose and point of view and organizes the research process

[43] Dharnidharka and et.al., "Across All Solid Organs, Adolescent Age Recipients Have Worse Transplant Organ Survival than Younger Age Children"; Dipchand and et. al., "The Registry of the International Society for Heart and Lung Transplantation."

[44] Dharnidharka and et.al., "Across All Solid Organs, Adolescent Age Recipients Have Worse Transplant Organ Survival than Younger Age Children"; Foster, "Heightened Graft Failure Risk during Emerging Adulthood and Transition to Adult Care."

[45] This is the term used by practitioners during transition clinics.

[46] Crowley et al., "Improving the Transition between Paediatric and Adult Healthcare."

accordingly"[47]—even as our understanding and research questions and strategies change over time.[48] His description aptly captures the transformation of my work from ethnographic fieldwork in a clinical setting into collaborative video storytelling research centering on the life-experiences of young heart transplant recipients. It was through clinical fieldwork that I became aware of the importance of storytelling as a measure of patient well-being and where transition, as a focus of study, transformed from a medical problem to be solved, to a more expansive subject. I elaborate on my approach to storytelling in Chapter 2. Here, I want to mark a shift in my own understanding of transition from the medical frame into a wider social-cultural frame. Like Victor Turner, I began to see transition as a process, a *becoming* and therefore an educational opportunity to support young people. Here too, insights from critical disability studies (CDS)[49] about the ways in which social-cultural practices frame disability in particular ways influenced the direction of my work. This dissertation, with its attention to the spaces betwixt and between is also a reflection of the insight from CDS research where precarity is understood as a way of life, and where what counts for normalcy or disability are not stable states of being but reflect an understanding that "ability" lies on a continuum precariously situated for each and everyone of us.

This dissertation explores transition as a process of being and becoming by examining how young people make sense of their experiences growing up as heart transplant recipients in a collaborative practice of video production designed to teach others about their lives. Video

[47] Vossoughi, "On the Formation of Intellectual Kinship," 86.

[48] Erickson, "Qualitative Methods in Research on Teaching"; Erickson, "Qualitative Research Methods for Science Education."

[49] Erevelles, "Educating Unruly Bodies"; Shildrick, "Critical Disability Studies"; Lester and Nusbaum, "'Reclaiming' Disability in Critical Qualitative Research: Introduction to the Special Issue"; Nusbaum and Steinborn, "'A "Visibilizing" Project: "Seeing" the Ontological Erasure of Disability in Teacher Education and Social Studies Curricula' by Nusbaum, Emily A.; Steinborn, Maya L. - JCT (Online), Vol. 34, Issue 1, January 1, 2019 | Online Research Library: Questia"; De Schauwer, Van De Putte, and Davies, "Collective Biography."

storytelling is an educational intervention. It provides a method and means for being and becoming as participants identify stories to teach while also reflecting back on their own experiences through the lens of learning (see Figure 1.1). In this study, I explore how young people continue to learn to care for themselves through their interactions with others within the context of existential precarity, where "learning to care" is an educational endeavor— learning as a way of life. In addition, the articulation of a philosophy of education as an ongoing process of life-long learning provides the *context* for this dissertation. For a study of how young people make sense of their unique life experiences is bound within practices of listening and telling, teaching and learning, being and becoming, analysis and synthesis. It is bound within an understanding that sense-making through storytelling, including the writing of this dissertation, is a collaborative, negotiated process of learning.

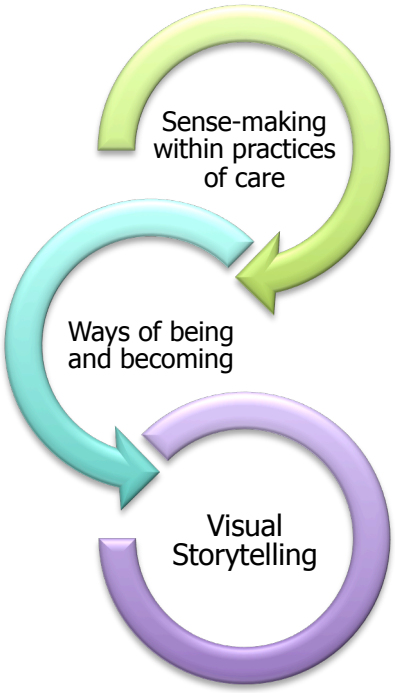

Figure 1.1 Linking *learning as becoming* to visual storytelling

Ethnographies of Education

In the tradition of ethnographies of education,[50] this dissertation is an ethnography of learning. Where most ethnographies of education examine learning in classrooms, I examine learning in informal environments.[51] Here too, there is a rich tradition of ethnographically informed studies of learning, particularly indigenous and culturally sustaining pedagogies[52] that inform my research. For if the intention is to enrich and sustain other approaches to education—to engage in social justice education—then this study also contributes to efforts of building sustainable ecologies to support young people in the spaces of transition. As an ethnography, my approach is participant-observation, where my participation is as important to this study as are my observations. What this means is that my own positionality within this study does not resolve into "a" place or "a" role, my status as participant-observer reflects a pedagogical commitment to youth participants and research. In this dissertation, the relations between teacher and student; ethnographer and heart transplant recipient; older and younger women—these roles are only the starting points from which we begin crafting stories of experience and transition. We, all of us, are betwixt and between and sense-making is our shared, on-going activity.

The Personal and Professional Context of Care

[50] Mead, *Coming of Age in Samoa*; Mills and Morton, *Ethnography in Education*; Levinson et al., *Ethnography and Education Policy Across the Americas*; Levinson and Pollock, *A Companion to the Anthropology of Education*.

[51] Rogoff et al., "The Organization of Informal Learning."

[52] Marin, "Learning to Attend and Observe"; Goodyear-Ka'ōpua, *The Seeds We Planted*; Paris, "Culturally Sustaining Pedagogy"; Paris and Alim, *Culturally Sustaining Pedagogies*.

My interests in learning and the relational implications of care formed over the course of my own education and with teachers who have had a profound impact upon my life. Though I elaborate more in the next chapter, here I wish to outline my stakes in this research.

As an undergraduate, I studied with the historian Carlo Ginzburg, an imposing and brilliant teacher. In our discussions, he admonished me to fight "predigested knowledge." For a young, somewhat naive, scholar this was a difficult and profoundly formative lesson. What it taught me was that sense-making—the effort to truly understand the complexity of any given topic—was a difficult and worthy task. It has been a challenging road. I was enrolled in doctoral programs first in the history of science and then cultural anthropology and found the expectations and environment deeply challenging. I left graduate school and for several years worked in television, an experience that gave me the skill set for collaborative video production. Ultimately though, it was motherhood that led to my return to graduate school.

Strangely, as a doctoral student in education I can count the number of times I have heard anyone mention parenting in discussions of learning. Other graduate students and professors routinely reference their role as classroom teachers to demonstrate their authority, but parenting, and the intimate relationships with children that it can foster go unmentioned. In my experience, parenting has everything to do with education. I returned to graduate school because as a parent I wanted to teach my child that the work of discovering and pursuing what is important to you—the challenges of coming-of-age— is a difficult but necessary endeavor. I wanted him to know that it is a path that can be undertaken no matter how many times you may have failed in the past. The only way I felt I could truly teach that lesson was by authentically embodying the philosophy that education is a way of life. This starting point has proven to be important, perhaps even more to me, as it has sustained me through the challenges and uncertainties of graduate school itself.

What drove me to return was my frustration with the ways in which I saw young people's voices, perspectives and opinions so readily dismissed. There was something about my daily and intimate parenting interactions that revealed to me a world of inquisitiveness, creativity and concern repeatedly ignored as subjects worthy of engagement by other adults. Perhaps it was this silencing, and my own memories of the difficulty of finding a voice within realms of power that felt exercised upon me, that made me especially attuned to youth voices as a teaching and learning process.

Scholars in the interdisciplinary field of childhood studies have revealed the complexity of children's lives and in the process highlighted the social, economic and linguistic labor and competences children perform everyday.[53] Their work shows the vulnerability and resilience of children at the forefront of contemporary global processes, who negotiate complex cultural transactions in a world of flow, boundary crossing and hybridity[54] —a world of instability, always betwixt and between. Young people are growing up in these existential spaces and how they make sense of their world, their forms of knowledge production are as crucial and vital as anyone's. In terms of biotechnological innovation, to date little work has examined the experiences of young people in this medical frontier.

Narrative Strategies

All writing is a form of storytelling. In this story, I endeavor to employ a text and a subtext that run throughout. I use this description not because I have mastered the art of writing. Rather it is a strategy I employ because I understand writing as a process of sense-

[53] Goodwin, *He-Said-She-Said: Talk as Social Organization among Black Children*; Orellana, *Translating Childhoods*; Stephens, *Children and the Politics of Culture*.

[54] Haraway, "A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980s"; Traweek, "Faultlines or How Modern Became Retro: An Historical Political Economy of Knowledge"; Hannerz, "Notes on the Global Ecumene."

making, of crafting meaning. In 1966 Roland Barthes asserted, "to write is today to make oneself the center of the action of speech, it is to effect writing by affecting oneself, to make action and affection coincide, to leave the *scriptor* inside the writing."[55] Barthes was arguing that "to write" corresponds to the "middle voice," neither active nor passive, but always inside the action. Similarly Hayden White showed how form and content are not discrete aspects of storytelling but are plaited together through narrative.[56] In this dissertation I engage *form*, *content*, *narrative*, three concepts central to the humanities and represented in medicine under the names Medical Humanities and Narrative Medicine, to clarify different aspects of my research process, teaching and learning process, as well as their intersection in collaborative storytelling. Barthes evocation of writing as an intransitive verb, where content and form are entwined, captures the struggle at the heart of this study, which is to make sense of the liminal spaces in-between being and becoming, teaching and learning, from a position inside the writing.

Text

The text of this dissertation is a case study that investigates a case: the design and execution of a collaborative video storytelling project. The three key participants of this project were myself, a doctoral student in education returning to the academy after work as a television producer; and two young women aged 26 and aged 14 who each had received a heart transplant in early childhood and had grown up in an environment where their normal daily activities included managing complex healthcare practices. In addition, Glen Ebesu, a professional editor and my spouse worked closely with us to assist us technically and edit the

[55] Barthes, "To Write: An Intransitive Verb?," 18.

[56] White, *The Content of the Form*; Ankersmit, Domańska, and Kellner, *Re-Figuring Hayden White*.

short films that were the product of this collaborative study. His artistic and technical contribution is acknowledged but not analyzed here. Instead, this study examines the give and take involved in crafting and producing the narrative arc of each short film. More specifically it is an ethnography of learning within our collaborative video production process. It is specific work that largely occurred in the interactions between myself and the younger women and it is these encounters that forms the focus of this study.

The encounters that resulted in two short films were framed at the outset as an educational endeavor: for the young participants it was an effort to teach others about their experiences in high-tech medicine while also learning elements of video production; for myself it was an effort to teach them how to construct a short narrative film while inquiring and learning about their lives, hopes and the perspectives that living with a heart transplant has offered them. This was also, from the start, an effort to provide an educational intervention, a means to support young people who had experienced a series of dis- and re-connections[57] from their schools, communities, families, friends, and peers by helping them craft stories about their lives to share and thereby also learn to recognize their work as accomplishments in learning to survive within the spaces opened by high-tech medicine. In these interactions listening even more than speaking was essential to learning.

Subtext

The sub-text of this study contributes to education by examining sense-making as forms of situated, partial knowledge production[58] in informal learning environments. This is a

[57] Yates led a remarkable team research study examining the impact of chronic illness on the lives of young people in Australia, *Keeping Connected*.

[58] Haraway, "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective."

departure from educational research that focuses on teaching and learning in classroom or workplace contexts where the focus is often pedagogy. Teaching and learning as part of a process of mastering skills or knowledge content and, in workplace settings, the development of a professional vision, or becoming a member of a particular learning community.[59] Here, I am interested in the possibility of building a common-sense,[60] —not a tacit knowledge, rather a shared understanding that participates in learning and teaching outside the model of education as the development of expertise.[61] Years ago, when I studied the history of science a common frame of analysis focused on problems of incommensurability,[62] punctuated moments of scientific theory that pushed forward new paradigms of practices. This was part of the historians attempt to make sense of Kuhnian[63] paradigm shifts. In this study I invert that frame by focusing on the possibility of commensurability. This is a gesture for connection, one that is also echoed by the American Educational Research Association's (AERA) recent annual meeting theme that pivots on the idea of a "future-oriented historiography" [64] as inspiration for "deliberate reconnection."[65]

[59] Goodwin, "Professional Vision"; Lave and Wenger, *Situated Learning*; Raia and Smith, "Practitioner's Noticing and Know-How in Multi-Activity Space of Patient Care and Teaching and Learning."

[60] Re-reading Sharon Traweek's chapter on narrative strategies and the damage caused by mis-reading frames this dream of a common-sense. "Border Crossings: Narrative Strategies in Science Studies and among Physicists in Tsukuba Science City, Japan," 438. I am also reminded by Ananda Marin that gestures of connection must also recognize incommensurability.

[61] Dreyfus, "Intuitive, Deliberative, and Calculative Models of Expert Performance."

[62] Biagioli, "The Anthropology of Incommensurability."

[63] Kuhn, *The Structure of Scientific Revolutions*.

[64] R.D.G. Kelley, "Culture@large: On Freedom and Radical Imagination" (American Anthropological Association, San Jose, CA, 2018); *Recording: Culture at Large 2018 with Robin Kelley*, 2019. See also "The need for a historiographical vanguard: an interview with Ewa Domanska," accessed July 21, 2019, https://hhmagazine.com.br/the-need-for-a-historiographical-vanguard-an-interview-with-ewa-domanska/.

[65] "2020 Annual Meeting Theme."

Pedagogical Commitments

In this dissertation the effort to forge connections is a critical pedagogical stance operating overtly in the practice of collaborative work in narrative video production, and analytically by paying attention to the process of sense-making individually, collectively and in the spaces in-between. In this respect, this study also builds upon the work of feminist technoscience scholars who have taught me to, 1) focus on knowledge production through cultural, philosophical, and ecological lenses;[66] 2) recognize one's own activity as also embedded within webs of knowledge and power in ways that may not be readily self-apparent; and, 3) harness this analytic insight to craft sustainable, livable spaces for being and becoming. Donna Haraway describes this mode of work as sympoiesis, a generative approach—which she defines as a process of 'making with'...that can only happen collectively and collaboratively."[67]

The text and subtext of this dissertation explicitly examine teaching and learning as a sympoietic process that begins from a critical stance in which care is not simply a mode of empathic practice.[68] Rather, in this study "care" is understood expansively, across multiple literatures, and implies:

- an accomplishment — through an exploration of how young people learn to care for themselves;

[66] Traweek, *Beamtimes and Lifetimes*; Sofoulis et al., "Coming to Terms with Knowledge Brokering and Translation. A Background Paper"; Sofoulis, "From Integration to Interaction"; Harding, *The Feminist Standpoint Theory Reader*; Tanio, "Gendering the History of Science."

[67] Kenney, "Donna Haraway (2016) Staying with the Trouble: Making Kin in the Chthulucene."; Dempster, "A Self-Organizing Systems Perspective on Planning for Sustainability"; Buchanan, "Sympoiesis."

[68] There are other analyses that see care, especially within organ transplantation as a debt—the responsibility of self-care —exacted upon transplant patients Sothern and Dickinson, "Repaying the Gift of Life." Though debt and its repercussions offer an important lens for understanding, it is outside the narrative of this dissertation.

- an educational intervention —a means to support young people through collaborative visual storytelling practices
- invisible labor[69]
- an ethical relational stance in education[70]
- an ethical stance in relation to research[71] that participates in an encompassing, but not uncritical, "ethics of promising."
- a Relational*Act*[72]

Care is already assumed to be part of the web of power inscribed in relations between individuals. In other words, this is not a tale about agonistic encounters between interlocutors and myself, medical professionals and young patients, teachers and students, or even parents and children. This study occurs within a culture and ecology of care and caring[73] that also resonates on the level of relational-ontology.[74] What this study examines is sense-making within practices of care: what it means to care for one another, what it means for young people to care for themselves and how caring intentions may have multiple consequences. Part One continues in Chapter 2 where I explain how storytelling emerged as a focus in ethnographic fieldwork and how I merge narrative and narrative inquiry into a conceptual critical framework, followed in Chapter 3, by an explanation of my methodological design.

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[69] Crain, Poster, and Cherry, *Invisible Labor*; Folbre, "The Invisible Heart: Care and the Global Economy"; Murphy, "Unsettling Care."

[70] Noddings, *Caring, a Feminine Approach to Ethics & Moral Education*; Noddings, "Caring in Education."

[71] Fortun, "For an Ethics of Promising, Or"; Fortun, "The Care of the Data."

[72] Raia and Deng, *Relational Medicine*; Raia, "The Temporality of Becoming."

[73] Mol, *The Logic of Care*; de la Bellacasa, "Matters of Care in Technoscience"; Stengers, "Introductory Notes on an Ecology of Practices."

[74] Raia and Deng, *Relational Medicine*.

Chapter 2 - Visual storytelling as a model of collaborative research

This chapter outlines storytelling as the conceptual framework for this study. As a practice, storytelling encompasses multiple meanings, histories, genres and voices. In this chapter I outline the reason for choosing visual storytelling as the mode of collaborative research with young people. In addition I provide a justification for visual narrative inquiry as the framework for knowledge production in this study. In this way, following Ravitch and Riggan, [75] storytelling is positioned as the overarching topic and method for educational research on youth experiences of transition in transplant medicine.

A narrative vignette

I'm surprised that storytelling is a central focus in the post-transplant pediatric cardiology clinic. Checking in, making sure patients have re-connected with their schools, re-connected with their friends is a consistent theme during patient's bi-annual appointments. The pediatric team is made up from multiple specialties including pediatric cardiology, social work, dietetics, psychology and dentistry. Each specialist meets with the patient and their family. And across their visits I hear them ask some version of the same question: "Is she telling her story?"

It is difficult to find your voice. Literally, intubation during transplant surgery can leave adults and young people (patients) without a voice. Usually this is a temporary, unexpected setback.

You have been diligent. You have prepared yourself, to the best of your ability, for your own wretched heart to be removed and replaced by one that only hours before beat in another's body.

[75] Ravitch and Riggan, *Reason & Rigor*.

You and your family have waited for that call, signed all the paperwork that authorized, legalized consent. If you are a minor, your parents and healthcare team have done this for you. They have authorized this transaction and prepared you to the best of their ability. You know what it is like to live with a weakened heart. It is ineffectual, exhausting, leaving you tired and bedridden, missing countless days of work and school to the frustration of your teachers, classmates, colleagues and family. This gift, you are contemplating, hoping for, this new heart is a huge chance. A new heart represents a new lease on life.

Imagine waking up, after you have prepared yourself for the trauma of transplant, only to discover you cannot speak. Whispering is a challenge. Swallowing is a challenge. You will be sent home with a colostomy bag for safe measure. "It's only temporary," they tell you. "You won't be able to wear a bikini," they tease." But to you it is heart-breaking.

Figuratively too, finding your voice is difficult. You have missed so much work, so many classes. The tendrils of friendship and kinship have been stretched, perhaps broken. You and your family are required to relocate to within an hour of the hospital for months at a time. You have existed in this liminal state, waiting, hoping for an offer, for as long as you can remember, awaiting a change in status until finally you find yourself one of the lucky ones. You, the recipient of a "gift of life" find yourself in a new land, with a renewed life.

This is not an uncommon experience. Dis-placed, dis-possessed, dis-membered, for young people growing up in this age of flow and hybridity, finding your voice in the aftermath of existential trauma is a shared challenge.

But this is uniquely your story. And how you craft that tale, who you choose to share it with and what you find salient or not, is part of the process of telling your story.

Storytelling and Experience

In 1936, Walter Benjamin mourned the ending of storytelling. He positioned storytelling as the sharing of experience that "goes from mouth to mouth" and pointed to a decline in storytelling in an age marked by technological and information transformation. He wrote:

> For never has experience been contradicted more thoroughly than strategic experience by tactical warfare, economic experience by inflation, bodily experience by mechanical warfare, moral experience by those in power. A generation that had gone to school on a horse-drawn streetcar now stood under the open sky in a countryside in which nothing remained unchanged but the clouds, and beneath these clouds, in a field of force of destructive torrents and explosions, was the tiny, fragile human body.[76]

The world in which young people with heart transplants are living, is a world very different from Walter Benjamin's and this dissertation is resolutely a practice of storytelling. Yet Benjamin's acute attunement to the fragility of the human body still resonates and the challenges of transforming experience into stories that can be transmitted mouth to mouth persist within experiences of biotechnological innovation.

A story can be a place or a tale. It can be the floor of a building or a "connected account of some happening."[77] *Storytelling* and *narrative* are about the activity and practice of telling stories.[78] Roland Barthes wrote that narrative was "international, transhistorical, transcultural: it is simply there, like life itself."[79] And yet, there is little that is simple about narrative.

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[76] Benjamin, "The Storyteller: Reflections on the Works of Nikolai Leskov," 84.

[77] "Story | Search Online Etymology Dictionary."

[78] "Storytelling, n."

[79] *Image-Music-Text*.

Etymologically to "narrate" comes from the Latin *narrāre* ("to tell") which is traced from *gnārus* ("knowing"), linked to the Greek *gignōskein*, whence *gnōsis*, and to the Sanskrit root *gnâ* (to know).[80] Thus storytelling is a form of knowing.

This dissertation emerges at the intersection of knowing and telling, focusing on accounts of a happening. The happening is storytelling itself: a collaborative video project aimed at creating stories to share with others about the experience of growing up with a heart transplant. My initial research questions (RQ) are broad and expansive:

RQ1: What does it mean to come of age, to grow up, within the age of high-tech modern medicine?

RQ 2: What stories do young people identify as important to share?

Although a more detailed description of our collaborative process is covered in Part Two, it is important to note that this project was designed, in part, as an intervention. Heart transplantation is unique to high-tech medicine, an experience unknown to all but a few.[81] This research afforded young people an opportunity to reflect upon their own experiences in order to teach others about their hard-earned expertise—work, I came to learn that was new to my participants. In return, I taught them elements of video production—from pre-production and production to post-production. Together, through collaborative production of visual stories, we created short films that tell young people's stories.

Still, even the short journey to *gnâ* engages in a particular, cultural, type of storytelling: storytelling as a search for roots—the tracing of origins as a means of justifying and authorizing its tale. In order to present storytelling as a form of inquiry, I trace its etymological connection

[80] Turner, "Social Dramas and Stories about Them," 163; "Narrate, v."; White, "The Value of Narrativity in the Representation of Reality"; Mikula, *Key Concepts in Cultural Studies*.

[81] Raia and Deng, *Relational Medicine*.

to knowing and in that move, neglect the ways in which storytelling is ubiquitous to many cultures and many ways of being and understanding.[82] The tension in that movement—between what it means to know and to speak, what it means to tell stories—is a tension that lingers throughout this study. Still, at the outset I wish to declare that the search for roots and origins—as common and ingrained in me as it is—is neither the primary genre nor impetus at play here.

Narrative inquiry in education research

Narrative inquiry in educational research emphasizes the telling of stories as "living, telling, retelling, and reliving stories of experience."[83] The emphasis on the experiential in narrative research has roots in the writings of John Dewey and his proposition that education is experience.[84] So to follow the "narrative turn" in educational research is to position one's work within the landscape of knowing that is always situated in experience. Here learning is always an intransitive verb.[85] It is always in the process of being and becoming.[86]

Storytelling offers an opportunity to listen and to tell, to teach and learn about other experiences and ways of being. It is poiesis, an instance of creative production.[87] Seen more expansively, Maxine Greene argues for the centrality of arts in education because "the arts can

[82] In particular I am referring to indigenous epistemologies and pedagogies which insist oral traditions are social, living, activities rather than "reified products" to be re-sourced. Cruikshank, *The Social Life of Stories: Narrative and Knowledge in the Yukon Territory*.

[83] Huber et al., "Narrative Inquiry as Pedagogy in Education," 213.

[84] Clandinin and Connelly, *Narrative Inquiry*.

[85] Traweek, "The Dilemmas of Writing in a Formal Style: Issues and Practices."

[86] Huber et al., "Narrative Inquiry as Pedagogy in Education"; Greene, "Diversity and Inclusion: Toward a Curriculum for Human Beings"; Clandinin and Connelly, *Narrative Inquiry*; Paley, *The Girl with the Brown Crayon*.

[87] "Poiesis, n."

awaken us to alternative possibilities of existing, of being human, of relating to others, of being other."[88]

An example of how stories open other worlds and understanding to us can be seen in Vivian Paley's *The Girl with the Brown Crayon.*[89] Paley interests include narrative inquiry and teacher education. During her last year of teaching, she designed a literacy curriculum consisting of reading and engaging with the illustrated books of Leo Lionni. In an extraordinary passage, Paley tells the story of two kindergarteners Reeny and Walter and what she learned by teaching, listening and engaging with them.

Reeny is the titular character — the girl with the brown crayon — an African American kindergartener whose artistic sensibility, thoughtfulness and engagement propels much of Paley's narrative.

Walter is an immigrant from Poland. A shy child, Walter sees himself as lacking both artistic and English-speaking skills. A component of Paley's literacy pedagogy is to have the kindergarteners expand upon Lionni's stories through their own art. Whereas Reeny eagerly accepts this challenge and draws herself and her classmates into Lionni's worlds, Walter's drawings throughout the year and across the curriculum consist of carefully colored squares. It is only after reading Lionni's *Pezzettino*,[90] a book in which the story is illustrated entirely through colored squares that an interpretative framework emerges for understanding Walter's art and positionality.

Throughout the year Walter has seen his own drawings as proof that he cannot draw. He sees himself as lacking. Notably, this is different from many discussions of deficit

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[88] "Diversity and Inclusion: Toward a Curriculum for Human Beings," 214.

[89] *The Girl with the Brown Crayon*.

[90] *Pezzettino*.

perspectives, for here his teacher, Paley sees Walter's fluency in Polish and writing as assets, even as Walter judges himself inadequate.

Reeny connects Walter's drawing to *Pezzettino* and through Reeny's insight, Paley comes to realize that the class reads *Pezzettino* not as a "peer-group" story but as the story of a child in the world of adults. This insight leads her to realize that if Walter's interpretation of "less than" is not situated in the world of peers, then it must come from the world of adults. Moreover, this world is not located in family life, where Walter is a fluent participant, but another world shaped by adults, the world of teachers and schools.

Paley asks: "When did I ever properly appreciate Walter's squares? Reeny perceives their artistic integrity, comparing him to Leo Lionni. His 'I not can it' is heard when the one-who-teachers comes around."[91] "Pezzettino is every child who has ever walked into a classroom. 'Do I belong here? Does someone care about me?' Perhaps the lonely island Pezzettino is sent to does in fact represent school, where children are broken into pieces in order that adults may observe, label, and classify them. And, having been so dissected, how does the child become whole again?"[92]

Paley uses her insight into the world of schooling to develop a vision of narrative inquiry as a search for *narrative continuity.* When her co-teacher reminds her that she once referred to play as narrative continuity, Paley responds, "That's exactly the point…It feels as though we are marching to that same rhythm, as in play...Let's face it, what school usually does is continually *interrupt* any attempt on the part of children to recapture the highly focused intensity of play. What we need to do is help them—and ourselves—get back on the track."[93]

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[91] Paley, *The Girl with the Brown Crayon*, 53.

[92] Paley, 53–54.

[93] Paley, 74–75.

Narrative inquiry as narrative continuity is one way in which Paley positions storytelling as a form of pedagogy. In their review of narrative inquiry in education, Huber et al. examine the transcendent power of story to connect across different experiences in time, place and communities. They review the emergence of narrative inquiry as research methodology linked to social justice movements, including counterstories[94] or counternarratives[95] that see, in stories, the possibility of teaching and telling alternative tales. Huber et al. characterizes this form of narrative inquiry as an ethical stance which insists on the tentative nature of knowing that comes with an "awareness of the multiplicity of perspectives over time."[96] Yet in their overview of the multiple strands narrative inquiry enacts as transformative pedagogy, one lesson absent is Paley's realization that narrative is not only a pedagogy or practice, storytelling is also the assumption of authority to speak. To engage in narrative inquiry as pedagogy is to position students not only as learners but also as teachers, where the question, "Do I belong?" can be answered in the affirmative by the acknowledgement that their experience is enough to begin storytelling.

That is the impetus embedded in this study. The focus of this research is not to tell a foundation story. Rather, by embracing storytelling itself, we enter a realm of knowledge production, education, in the intransitive spaces of poesies. That is our starting point. I begin at storytelling because to be a storyteller is to take a risk, to be made vulnerable to censure, critique, and judgment even as we authorize ourselves. My focus is storytelling, even as I am also made aware by Delpit and others[97] of the many ways in which the silencing of voices—both

[94] Huber et al., "Narrative Inquiry as Pedagogy in Education," 229–31.

[95] Solórzano and Yosso, "Critical Race Methodology."

[96] "Narrative Inquiry as Pedagogy in Education," 229–31.

[97] *Other People's Children*; Valenzuela, *Subtractive Schooling*.

actively and benignly—is also constitutive of the history of narrative inquiry in education.

From Poiesis to Sympoiesis

Classical philosophy of education teaches us that education—the construction of wisdom (*paideia*, *bildung*) is also a way of life.[98] Education and its philosophy are embedded in a history of powerful practices that marginalize many learners.

When I was in third grade I was given an IQ test. At the time I was living in military housing in West Germany attending a school run by the Armed Services for children of military personnel. I imagine the experience was much like any public school in America except that if the station was "on alert" it meant that students, whose classrooms were often scattered around the base, could be confronted with armed uniformed military personnel holding gas masks who would yell at us to get back inside.

In the third grade my classmates and I were given a test. I remember adults conferring in my classroom and looking over in my direction sometime afterward. My results indicated that I was an outlier. Seemingly overnight I moved through successive classrooms to end up in an advanced math grouping.

I remember being somewhat bewildered by the changes but also intent on succeeding and being worthy of my new circumstances. Family life was not a place of learning or empowerment. My father asked me if I was lying about my changing circumstances at school. Thereafter a disjunction between school and home opened up for me and the classroom became a place of possibility and connectedness, an opportunity for learning, self-discovery, and powerfully, for recognition. Learning, schooling, education these intertwined activities

[98] Kellner, "Toward a Critical Theory of Education"; Hadot and Davidson, *Philosophy as a Way of Life*.

began to resonate with me but they were practices that resulted in both joy and pain, as I struggled to make sense of structures, histories and experiences hitherto foreign to me.

Socialization is often characterized as a linear, stable process, a journey from novice to expertise.[99] Yet my own educational journey is far from that model, failures often mixed with successes, circling back many times, with a hope that experience is education and that I have accumulated worthwhile experiences and lessons along the way.

As a young student, schools were institutions that could be bureaucratically indifferent or supportive. They remain formative sites of childhood. I was fortunate in that my test scores resulted in a reclassification within that institution. They signaled to my teachers and myself that I had untapped potential. Classrooms can be instruments of sorting and disciplining and, through the work of teachers and students, classrooms can also be sites where the promise of education is realized. My relationships with teachers were often key. A needy child in search of approbation and affirmation, I took my cues from them.

Because education is defined, in part, by powerful and unequal relations, Nel Nodding's characterization of care as a critical framework that should guide the interactions between teachers and students remains vitally important to me.[100] I have been fortunate in my own teachers. From Miss Anderson, an idealistic young teacher who taught me to read in first grade over countless lunch periods, to Mrs. Chmelar, my third grade teacher, an exemplar of a caring professional, the grade-school teachers I remember best were ones who understood care as a fundamental educational act.

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[99] Dreyfus, "Intuitive, Deliberative, and Calculative Models of Expert Performance."

[100] *Caring, a Feminine Approach to Ethics & Moral Education*; *Stories Lives Tell*.

Many children are not as lucky. Tisa Bryant[101] describes the relentless disciplining hand of the teacher evident in Octavia E. Butler's early manuscripts. For Butler, who graduated in the bottom of her high school class, schools were a place of marginalization and alienation. Butler once told an interviewer, "I began writing about power because I felt I had so little."[102]

For the participants in this study, schools have been a place of disconnectedness. Their experiences of growing up with chronic illness, heart failure and heart transplantation have resulted in long absences and resettlement. And their reintegration into schools turned into the question, "Is she telling her story?"

Stories as World-building

Octavia E. Butler was the first science fiction author to win a MacArthur Fellowship. Upon discovering that there were no fully-realized black characters in science fiction, Butler decided to "write myself in since I'm me and I'm here and I'm writing".[103] Her stories centered the lives of black women to envision new worlds and ways of being.[104] Butler took an old genre like the alien invasion story and innovated it to create "speculative fabulations"[105] stories that mined earth-bound biological sciences and human history to imagine hybrid, fluid, alternative possibilities and futures.

In speculative fiction this work is called "world-building."[106] Although the term has a longer history—the OED's earliest quotation is from 1820—in science fiction and fantasy world-

[101] "Hand of the Teacher."

[102] Davidson, "The Science Fiction of Octavia Butler."

[103] Fox, "Octavia E. Butler, Science Fiction Writer, Dies at 58."

[104] *Kindred*; *Dawn*.

[105] Bahng, "Plasmodial Improprieties."

[106] Roine, "Imaginative, Immersive and Interactive Engagements. The Rhetoric of Worldbuilding in Contemporary Speculative Fiction."

building is a defining feature of the genre, one, that like plot or character, is a criteria on which a work is judged. Although those questions are not paramount here, it is precisely Butler's world-building that continues to provoke and inspire.[107]

In Butler's work, world-building can be understood as both the construction of fantastical worlds and the process of writing oneself into the narrative. Butler's tales participate in a black, feminist, science-fiction practice that resists utopian visions and insists on the materiality, cost and necessity of compromise in order to create livable, sustainable, and speculative futures.

It is interesting to juxtapose Octavia E. Butler's speculative world-building with the work of Judith Butler, a critical theorist whose work explores issues of violence, precarity and the possibility for more viable, livable lives.[108] Judith Butler's analysis is increasingly engaged in the contemporary moment, where certain lives are cast so outside the public sphere as to be considered unmournable.[109]

Though Judith Butler is interested in analyzing the exercise of political, social and cultural power on individual lives, her focus on the precariousness of life as an existential human fact reverberates across this study, where young people negotiate chronic illness, instability and indefinable futures with heart transplants. I find in both Octavia E. and Judith Butler an ethic, a way of being and looking, that recognizes precariousness and seeks to craft livables spaces for being human. Nevertheless, it is Octavia E. Butler's work in speculative

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[107] There has been a recent proliferation of Butler scholarship, see for example the two volume special issues in *Women Studies* "Octavia Butler, Part One"; "Octavia Butler, Pt. II." and the presentation and conference linked to the opening of Butler's archive at the Huntington Library "Octavia E. Butler: Telling My Stories"; "Octavia E. Butler Studies: Convergence of an Expanding Field."

[108] Butler, *Precarious Life*; Butler, *Notes Toward a Performative Theory of Assembly*; Butler, *The Psychic Life of Power*.

[109] Butler, *Precarious Life*.

world-building where I find the possibility of collaborative work as sympoiesis.[110] For, in the midst of poverty, ill-health and self-doubt, Butler sustained herself by creating stories and worlds about working-with, making-with, forms of sympoiesis that opened spaces of possibilities for her characters, but also enabled others, like me, to enter and participate.

Stories as becoming

This study contributes to the philosophy of education by examining learning outside of schooling, as a way of life: stories as becoming. My sense of storytelling is indebted to indigenous scholarship which insists that learning impacts epistemological and ontological registers of becoming.[111] It also closely aligned with the educational literature on "learning as becoming," a term introduced in 2009 by Hager and Hodkinson that sees learning as a social, embodied and never-ending process "within a transitional process of boundary crossing."[112] Emerging from cognitive psychology perspectives which sought to move beyond "transfer learning" as the principle metaphor for understanding learning not as a discrete act, but as a process. Learning as becoming has proven to be a rich metaphor often used in studies of workplace learning.[113] Despite its recent use within cognitive psychology and the learning sciences, learning as becoming has a longer tradition linked to continental philosophy, existentialism, and the work of Martin Heidegger. This more expansive perspective is central in

[110] Dempster, "A Self-Organizing Systems Perspective on Planning for Sustainability"; Kenney, "Donna Haraway (2016) Staying with the Trouble: Making Kin in the Chthulucene."

[111] Cajete, *Look to the Mountain*; Cruikshank, *The Social Life of Stories: Narrative and Knowledge in the Yukon Territory*.

[112] Hager and Hodkinson, "Moving beyond the Metaphor of Transfer of Learning"; Singh, "Learning as Becoming and Implications for Curriculum | The Education and Development Forum."

[113] Hager and Hodkinson, "Becoming As an Appropriate Metaphor for Understanding Professional Learning"; Malloch, *The SAGE Handbook of Workplace Learning*; Boud and Hager, "Re-Thinking Continuing Professional Development through Changing Metaphors and Location in Professional Practices."

the work of Federica Raia[114] who argues that the lens of learning extends the metaphor of learning beyond an epistemological process of knowing to an ontological register of learning, understanding and becoming.[115]

Of course, neither education nor philosophy own monopolies on theories of becoming.[116] Childhood has never been a stable stage of being. Children are often viewed within a developmental lens of becoming adults.[117] Yet the interdisciplinary field of childhood studies[118] challenges that paradigm by insisting that there is an ongoing tension and legitimate need to see children as both *beings* and *becomings*—as social actors in their own right and as the inheritors of the future.[119] As childhood scholars have shown, there is extraordinary richness in seeing children as complex actors by illuminating the linguistic and cultural labor of children within families,[120] and within peer groups.[121]

These works reveal children navigating, mediating and constructing their own pathways within the institutions (families, schools, public services) that structure their lives. Still, though boundaries may blur, a difference between childhood and adulthood is undeniable. The late Sharon Stephens, whose introduction to *Children and the Politics of Culture*,[122] remains a vital

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[114] Raia and Deng, *Relational Medicine*; "Identity, Tools and Existential Spaces - ScienceDirect"; Raia, "Practices of Care."

[115] Raia, "Identity, Tools and Existential Spaces."

[116] See for instance Michelle Obama's bestselling autobiography.

[117] Mayes, "Shifting Research Methods with a Becoming-Child Ontology."

[118] Bluebond-Langner and Korbin, "Challenges and Opportunities in the Anthropology of Childhoods"; James and Prout, *Constructing and Reconstructing Childhood*.

[119] Qvortrup, "Placing Children in the Division of Labour."

[120] Orellana, *Translating Childhoods*.

[121] Goodwin, *He-Said-She-Said: Talk as Social Organization among Black Children*; Goodwin, *The Hidden Life of Girls: Games of Stance, Status, and Exclusion*.

[122] *Children and the Politics of Culture*.

touchstone for childhood studies, argued that childhood was increasingly "threatened, invaded, and 'polluted' by adult worlds."[123] This threat, she argues, is *the* politics of culture where what is at stake is not only our notions of "innocence, but of nature, individual freedom, social values of enduring love and care (as opposed to temporally restricted economic and bureaucratic transactions)…".[124] Though Stephens implies a sharp binary opposition between children and adult worlds, reinforcing a particularly Western view of childhood, her recognition of childhood as culturally complex, distinct, and under threat, echoes Judith Butler's work on precarity and vulnerability. Many others scholars navigate the fluidity between the worlds of childhood and adulthood.[125] In fact, the transition between these worlds and the challenges and responsibilities that emerge is a central focus of this study. Another focus is the work of collaboration. One that situates this research as the negotiation of educational encounters between young people and myself as we build collaborative, visuals stories inscribed within unequal relations of power, understanding, histories and identities.

Stories from betwixt and between

The young participants in this study inhabit neither Octavia E. Butler's speculative fabulations nor the cyborg imaginaries of feminist science studies.[126] Within a world of flow, boundary crossings and hybridity,[127] young people are positioned at the cutting edge of pioneering technology and knowledge production. Their experiences and the stories that

[123] Stephens, 9.

[124] Stephens, 9–10.

[125] Rogoff, *Apprenticeship in Thinking: Cognitive Development in Social Context*; Marin, "Learning to Attend and Observe"; Orellana, *Translating Childhoods*.

[126] Haraway, "A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980s"; Sofoulis, "Cyberquake: Haraway's Manifesto."

[127] Haraway, "A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980s"; Traweek, "Faultlines or How Modern Became Retro: An Historical Political Economy of Knowledge"; Hannerz, *Flows, Boundaries and Hybrids*.

emerge are part of a world-building process in which knowledge—experiential, scientific, provisional—is also being constructed.

Though the voices of young people are often discounted and marginalized, especially in scientific discourse, there are other models to guide us: I borrow from Zoë Sofoulis, the idea of "knowledge ecology," a metaphor that implies "groups of diverse players of different sizes and roles, each finding their niche in a system of knowledge flows."[128] In an ecosystem of high-tech medicine, where medical professionals, family caregivers and pediatric patients are all key players finding their niche, my hope is that a knowledge ecology framework might provide an alternative vision, one that recognizes the expertise of young people as participants in helping solve the challenges of transition through storytelling.

Ananda Marin[129] uses walking as a methodological lens for understanding the ways in which indigenous science is taught and learned within families in ways *other than* an objectified examination of nature. Her sense of motion propels an understanding of learning and teaching, that is embodied, provisional, and indebted temporally and geographically to the land. Movement is both a metaphor for education contra the long and well-respected metaphor and practice of learning as a search for origins used to explain, discover, defend, the essence of a story *and* the means for examining indigenous science education.

From Marin I borrow the sense of movement. Where her work is intimately tied to family storytelling practices about and within the natural world, my use of motion is situated within worlds of storytelling: the making, constructing, and remaking of stories about the complex coming-together of bodies and technology, adolescence and adulthood, teaching and learning.

[128] Sofoulis et al., "Coming to Terms with Knowledge Brokering and Translation. A Background Paper"; Sofoulis, "From Integration to Interaction."

[129] "Learning to Attend and Observe."

In this dissertation I trace stories of becoming, stories of practice, stories of learning and of teaching, stories of survival. These stories all involve a collaborative and creative process of storytelling with young people who received heart transplants as children and are in the midst-of, or have recently completed their transition from pediatric to adult care.

Like most dissertations this work is also engaged in a type of storytelling. Dissertations are a specific genre of story often following a highly prescribed pattern. Yet here I try to tell a different type of story, not quite a counter-narrative, but one embedded, as you have read, within its own multiple encounters and histories. Like many stories of encounter, these stories are contested spaces, spaces of both silencing and possibility. My engagement in that contestation is through the act of storytelling. That is the imperative that propels this project: to make sense of individual life experiences in collaboration with another; to give voice to stories lived, imagined, and hoped for; to learn, through the practice of storytelling the many ways to recognize another in order to foster livable spaces for being and becoming part of an ecosystem of care.

Chapter 3 - Methods

In this chapter I discuss my methodological approach. If Chapter One tells how this project developed, and Chapter Two traces storytelling as an educational endeavor then this chapter describes how I went about the research.[130]

Methods are more than a set of procedures to be followed. Methods embody an ethical stance, a way of seeing, thinking and living with the subject matter at hand. Like a classroom teacher who has created her lesson plan in advance yet must also be attuned to the needs of her students, as a researcher and practitioner, I needed methods that were specific yet flexible to unfolding interactions and encounters. My methods needed to adjust to the challenges presented by each video production project; as well as attuned to the relational engagement, the tracings of teaching, learning, power, and knowledge that we enmeshed ourselves in in the making of each film.

Filmmaking is largely a problem-solving activity. It hinges on a story, of course. Still, so much of the work involves managing problems: How can we translate this idea into a visual and aural experience? What can we accomplish in the two minutes until we lose this location, or this speaker, or this light? How can we salvage bad audio? At each stage in the crafting of a film, problems large and small arise that need to be addressed and resolved simply in order to complete the film—regardless of whether that film is good or bad, enlightening or not. Similarly, I have found educational research to be a process of problem solving: How do you salvage a lesson plan that has gone off the rails? How can I make the best use of the limited time I have with a participant? There are crucial differences as well. Ethnographic research in education is more than simply problem-solving. As a participant and an observer, a teacher and a learner, it

[130] Shirin Vossoughi's work, especially her dissertation chapter on methods, was a helpful template in navigating my way through the challenging knots of this section.

means understanding and recognizing that the people you engage with have their own ways of seeing and sense-making. They have their personal histories and cultural perspectives that shape their experiences which may not be readily apparent. It requires an openness to learn and engage with another's point of view, even as they may be learning and discovering their perspectives in interactions with you.

Methodological framework

At the start of research, I presented potential participants with an opportunity to work with me on an educational film project. Each project forms a case. The steps to complete the films shaped the research trajectory. In this way, this research is a case study of two visual storytelling projects. Infusing each case were educational encounters that traverse unequal relations of power, age, experience, and status. Hence, each case reflects a narrative portraiture of collaborative visual storytelling[131]—an ethnography of learning. The challenge designing a method of research was also the challenge of keeping an open critical stance. It was the challenge of understanding that the entire project participated in a practice of sense-making bounded by my understanding of care as an ethical and pedagogical commitment. Part of this ethnography is a story of how a research method unfolds in the midst of interactions. These moments are detailed in Part Two. For now, I wish to outline the differing scholarly traditions that informed my own approach to methods and how I utilized and transformed them for this study.

Methodological Tools

Storytelling as co-telling

[131] Lawrence-Lightfoot and Davis, *The Art and Science of Portraiture*.

Storytelling—the telling and listening to a story—is always a collaborative process. At the start I knew that crafting a short film, especially with inexperienced filmmakers, would require collaboration at every turn. Unlike professional producing, which often necessitates telling others how to proceed, my role as a producer in this study was more informed by a storytelling approach to literacy that encourages young children to dictate their stories to teachers.[132] Here too, Vivian Paley's approach is often cited as inspiration even in visual literacy efforts like Wendy Ewald's multiple collaborative photography projects with young people.[133] Ewald describes her challenge in each project as learning to recognize "what they were seeing, and what kind of questions their vision asked of the world."[134] This study required something slightly different, for although I was also challenged to recognize what kinds of questions my participants asked of the world, there was an added layer in negotiating interactions between our roles as teacher and student, producer and storyteller that went beyond dictation or interpretation and into a realm of collaborative co-telling. Ochs and Capp's discuss "active co-tellership" as a way interlocutors shape narratives together and they identify a spectrum that runs from "high active" to "low active" participation in co-tellership events.[135] Yet this description does not quite capture the practices of co-telling involved in this study. The films we created are not véríte documentaries, they are composed, crafted through an aesthetic process of telling, retelling, refining and editing in which co-telling is always an embedded practice. To

[132] Paley, *Wally's Stories*; Cooper, "Literacy Learning and Pedagogical Purpose in Vivian Paley's 'Storytelling Curriculum'"; Wright et al., "Windows into Children's Thinking."

[133] Luvera, "Tools For Sharing." See also: Ewald, *Secret Games: Collaborative Works with Children 1969-1999*; Ewald, *The Best Part of Me*; Ewald, *Literacy & Justice through Photography*; Ewald and Lightfoot, *I Wanna Take Me a Picture*.

[134] *Secret Games: Collaborative Works with Children 1969-1999*, 18.

[135] *Living Narrative*.

capture that sense of collaboration I found Third Space theory[136] a useful guide to negotiating my role as a co-teller. Gutiérrez and colleagues, who build upon Moll's Funds of Knowledge approach,[137] argue for dialogic[138] models of instruction that recognize the socio-cultural assets minoritized students bring to their classrooms. The metaphor of a Third Space, as an alternative space for instruction, appealed to me because, like transition, it captures a sense of the hybrid, sympoietic spaces that teaching and learning within an ethics of caring can provide. Still, there were lingering and important differences. Third Space theory provides a framework for thinking about how to support young people as learners. In that, it is a model of pedagogy. However, as a researcher, I also recognized that there would be times in which the position of teacher and student would be inverted, times when I would need guidance in order to learn and understand the challenges of transition in high-tech medicine.

Visual research traditions

I used a storytelling prompt as the starting point for filmmaking. In each case, I asked participants to choose stories to share with others about the experiences of growing up with a heart transplant. This prompt framed this study as an educational endeavor. I wanted participants to identify salient lessons they would teach others about their experience. This placed participants in the position of expert. They were experts in their lives who had unique knowledge that even other adult heart transplant recipients did not share. This framing also shaped how visual methodology was used as a tool in this study.

[136] Gutiérrez, "Developing a Sociocritical Literacy in the Third Space"; Gutiérrez et al., "Building a Culture of Collaboration through Hybrid Language Practices."

[137] "Funds of Knowledge for Teaching: Using a Qualitative Approach to Connect Homes and Classrooms."

[138] Both Ochs and Capps and Gutiérrez and colleagues cite Bahktin as influential to their models of communication.

There are multiple approaches to visual methods[139] many in the tradition of Bateson and Mead's groundbreaking work in visual anthropology.[140] Within educational research visual methods are commonly used as research tools.[141] Cameras too, have been used effectively in classroom research and YPAR studies.[142] More recently, other multimedia technologies, including filmmaking, digital storytelling and photo-voice are becoming more common outside the classroom, especially as youth culture becomes more closely associated with media culture.[143]

Outside of educational research, filmmaking has a long history in the social sciences, especially in anthropology where, since the 1970s, "indigenous" filmmaking has been used in collaborative projects to turn image-making into a joint task with the hope that, "such image production would reveal what members of a culture themselves viewed as most significant."[144] This approach was also adopted in the field of medicine by the Video Intervention/Prevention

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[139] One source I found particularly illuminating is "The Natural History of an Interview" a multi-authored manuscript by Gregory Bateson and Ray Birdwhistell among others, that reads as a historical document of the foundation of modern social science visual research methods.

[140] Bateson and Mead, *Bathing Babies in Three Cultures*; Bateson and Mead, *Balinese Character*; Jacknis, "Margaret Mead and Gregory Bateson in Bali: Their Use of Photography and Film"; Tanio, "Photographier Bali: La Vision, La Reflexivite et Le Reel Ethnographique."

[141] Wissman et al., "Cultivating Research Pedagogies with Adolescents"; Raia and Smith, "Practitioner's Noticing and Know-How in Multi-Activity Space of Patient Care and Teaching and Learning"; Marin, "Learning to Attend and Observe"; Yates, *Keeping Connected*.

[142] Orellana, "Space and Place in an Urban Landscape"; Share, "Cameras in Classrooms"; Vossoughi and Escudé, "What Does the Camera Communicate?"; Wiseman, Mäkinen, and Kupiainen, "Literacy Through Photography."

[143] Kellner, "Multiple Literacies and Critical Pedagogy in a Multicultural Society"; Kellner, *Media Culture*; Blum-Ross, "Filmmakers/Educators/Facilitators?"; Ratto and Boler, *DIY Citizenship*; Prensky, "Digital Natives, Digital Immigrants Part 1"; Greene, Burke, and McKenna, "A Review of Research Connecting Digital Storytelling, Photovoice, and Civic Engagement."

[144] Harrison, "Seeing Health and Illness Worlds - Using Visual Methodologies in a Sociology of Health and Illness: A Methodological Review," 861; Ramella and Olmos, "Participant Authored Audiovisual Stories (PAAS): Giving the Camera Away or Giving the Camera a Way?"; Ruby, "Speaking For, Speaking About, Speaking With, or Speaking Alongside — An Anthropological and Documentary Dilemma."

Assessment (VIA) project at Children's Hospital/Harvard Medical School.[145] The VIA project gave video cameras to young people and asked them to record visual diaries. These diaries were filmed over several months and then reviewed and analyzed by medical research teams to study a variety of illnesses.[146] VIA helped researchers gain insight into "apparently counterproductive patient behaviors"[147] and resulted in targeted care strategies sensitive to the context of young people's lives. For example, VIA studies of asthma revealed known triggers in the homes of 95% of the participants that were not disclosed in their medical histories. Using these visual narratives, clinicians were able to point to patient's personal experiences as pedagogical tools to support better self-management of asthma.

Each of these iterative ways of using video as a method informs my collaborative storytelling method (See Figure 3.1). Still, following Walter Benjamin's assertion that stories allow for "narrative amplitude,"[148] there was something both more specific and more generalizable in my use of video narrative as a method centered on storytelling. For one, I was asking participants to answer a question they had been asked multiple times in the context of a clinical visit. In this study, they were allowed to respond to the storytelling prompt by addressing audiences that lay beyond the walls of a clinic, choosing topics that were salient to their lives with the understanding that they would be supported in the work of crafting their visual narrative because I had a vested interest in learning their stories. This prompt alone was

[145] Chalfen and Rich, "Applying Visual Research Patients Teaching Physicians Through Visual Illness Narratives"; Rich, Polvinen, and Patashnick, "Visual Narratives of the Pediatric Illness Experience"; Rich et al., "Video Intervention/Prevention Assessment: A Patient-Centered Methodology for Understanding the Adolescent Illness Experience."

[146] Buchbinder et al., "Assessing Adolescents with Insulin-Dependent Diabetes Mellitus"; Chalfen and Haley, "Reaction to Socio-Documentary Film Research in a Mental Health Clinic"; Rich and Chalfen, "Showing and Telling Asthma."

[147] Rich, Polvinen, and Patashnick, "Visual Narratives of the Pediatric Illness Experience."

[148] Benjamin, "The Storyteller: Reflections on the Works of Nikolai Leskov."

a recognition and affirmation that participants had more than one story to tell, and the journey lay in openness to discovering and crafting their stories together.

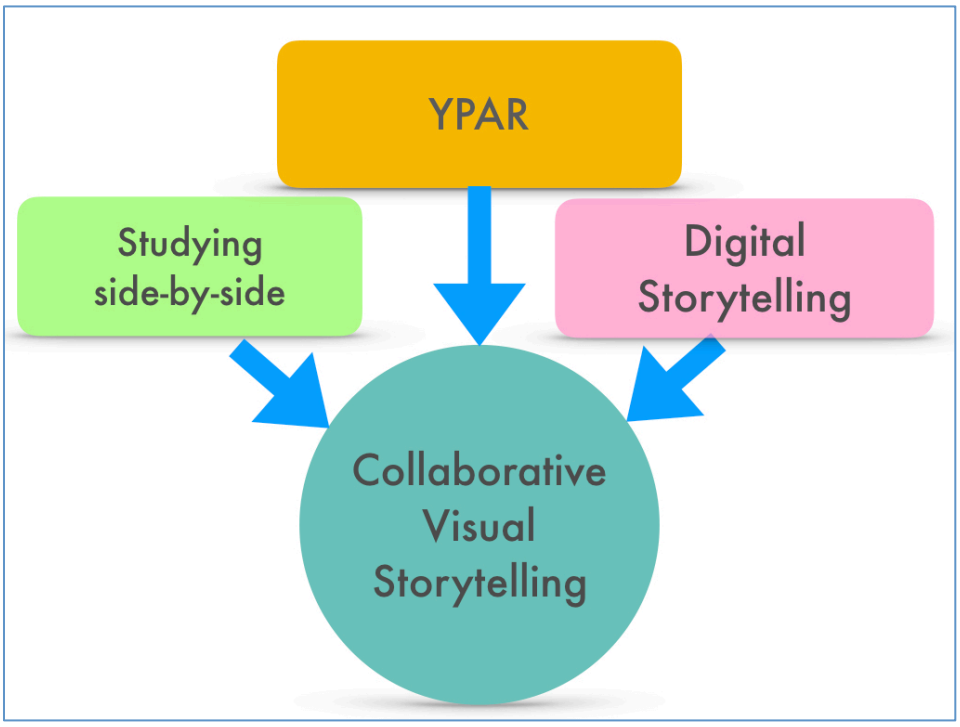

Figure 3.1: Shaping a research method

Critical Collaborative research

This study was designed as youth participatory action research (YPAR)[149] on collaborative visual storytelling. The participants were a young adult and an adolescent and their status as "youth" was vis-à-vis my own status as an older adult. Situated between critical media literacy production[150] and pedagogies of transformational resistance,[151] my aim was to

[149] Cammarota and Fine, *Revolutionizing Education*.

[150] Kellner and Share, "Toward Critical Media Literacy: Core Concepts, Debates, Organizations, and Policy"; Hammer, "Critical Media Literacy as Engaged Pedagogy."

create participatory spaces for young people through the production of educational videos. Elden and Levin suggest using "co-learning" as a way to capture the cogenerative approach to learning in participatory action research.[152] Yet there is an important difference, for unlike many YPAR projects [153] in which defining common research questions is part of the collaborative work, I borrowed Frederick Erickson's description of participatory research as a practice of studying side-by-side[154] to reflect how differential goals between researcher and participant might still enable collaborative research (see Figure 3.2 which outlines the differential goals and research responsibilities by participant).

YPAR presumes young people have the right to participate in research that focuses on their lives and experiences.[155] Like other methods of participatory research, YPAR is a recognition of and attempt to disrupt traditional power dynamics and hierarchies between observers and observed.[156] It is action research in that it "represents a fundamental, critical strategy for youth development, youth based policy-making and organizing, and education."[157] And, it often employs a visual methodology in the belief that visual forms of communication

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[151] Cammarota, "Youth Participatory Action Research: A Pedagogy of Transformational Resistance for Critical Youth Studies."

[152] "Participatory Research at Work: An Introduction," 2.

[153] Tuck, "Theorizing Back: An Approach to Participatory Policy Analysis"; Bellino and the Kakuma Youth Research Group, "Closing Information Gaps in Kakuma Refugee Camp: A Youth Participatory Action Research Study."

[154] Erickson, "Studying Side by Side: Collaborative Action Ethnography in Educational Research."

[155] Bradbury-Jones and Taylor, "Engaging with Children as Co-Researchers"; Cammarota and Fine, *Revolutionizing Education*; Cornwall and Jewkes, "What Is Participatory Research?"; Robson, "The Right to Be Properly Researched. How to Do Rights-Based, Scientific Research with Children."

[156] Caraballo et al., "YPAR and Critical Epistemologies: Rethinking Education Research."

[157] Cammarota and Fine, *Revolutionizing Education*, 16.

facilitate young people's "voice"[158] by providing opportunities "to explore, analyze and represent their perspectives in their own terms."[159] Nevertheless, even as I embraced YPAR as a disruptive methodology and my own inexpertise as a research practitioner, I was keenly aware of the power disparity that my age and status provided by both university affiliation, and the familiar teacher-student paradigm. To mitigate this inequality, at the outset of each collaborative film, I outlined an informal contract, a way of negotiating common ground by explicitly articulating my researchers goals and responsibilities while soliciting open and evolving participant goals followed by a set of responsibilities that guided our working relationship.

In this study, young people participated because they wanted to: 1) share stories about their experiences to an interlocutor, 2) create stories to share with a wider audience, and 3) because they wanted to learn the process of visual storytelling in order to participate in storytelling and media production on their own. Alternatively, my commitment to this research is based on my belief that, 1) education is a fundamental right[160] difficult to access, that is both dignity-conferring and rights-generative,[161] 2) that stories open spaces of possibilities to make sense of, and imagine alternative ways of being and becoming; and 3) that narratives are essential to understanding another's experience and perspective in order to build a common-sense for learning and action. Enmeshed within an ethics of care, researchers and participants relied on each other in order to successfully co-construct our collaborative short film.

[158] Yates, "The Story They Want to Tell, and the Visual Story as Evidence."

[159] Cornwall and Jewkes, "What Is Participatory Research?," 1671.

[160] Du Bois, "The Freedom to Learn."

[161] Espinoza and Vossoughi, "Perceiving Learning Anew: Social Interaction, Dignity, and Educational Rights."

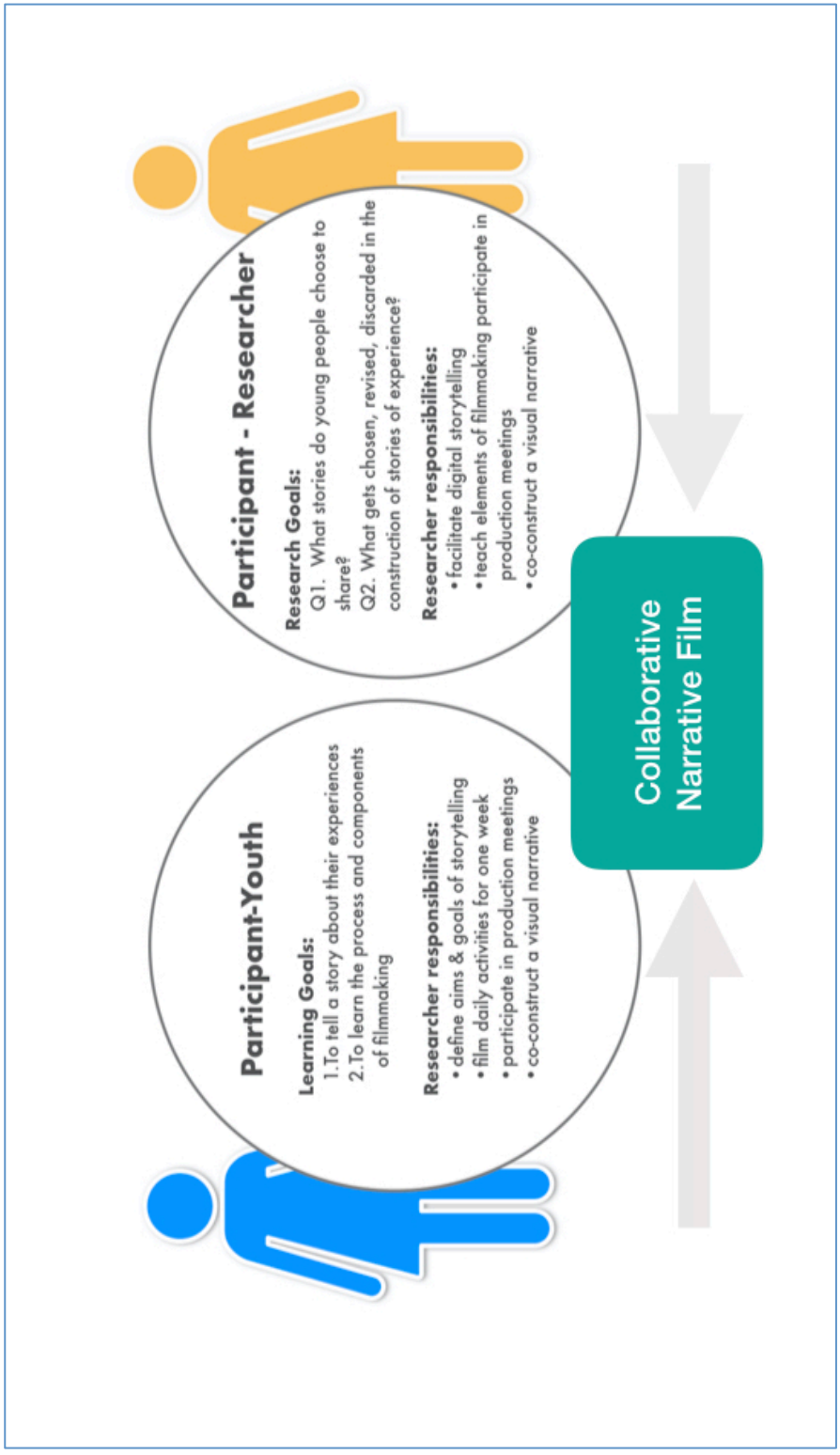

Figure 3.2 Goal and responsibilities across participants

Research Design

Unit of Analysis and Lines of Inquiry

In *The SAGE Handbook of Qualitative* Research, Denzin and Lincoln present several definitions of case study and end their entry with Thomas Schwandt and Emily Gate's contention that "there is not a single understanding" of what constitutes a 'case study' or the 'case.'[162] Its meaning can vary across disciplinary tradition and research approach. In this critical ethnography, each short film forms a case study—"a detailed examination of one setting, subject or event."[163] Here, each "event' is the making of a short film. Each "case" allows me to examine the practices and processes engaged in completing a collaborative narrative project. Yet in that effort, my interests are ethnographic. I am interested in understanding the processes of sense-making in the interstices of storytelling. In this way, this study is a "telling case," not because the stories we co-created are universal, they are not. Rather they are *telling*, because they are based upon unique experiences situated in time and place, a set of conditions per Benjamin[164] that opens a space for others (listeners, viewers, readers) to understand and participate in building a common-sense.

As an educational researcher I was interested in understanding what stories young heart transplant recipients identified as important to share. I wanted to trace what got chosen, revised, and/or discarded in the construction of stories of experience and how those decisions were made. Because I had worked in media production previously, and because our goals included teaching and learning aspects of media production, research was organized to mirror professional productions by staging our work within three phases (Figure 3.3):

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[162] Denzin and Lincoln, *The SAGE Handbook of Qualitative Research*, 315.

[163] Vossoughi "On the Formation of Intellectual Kinship," 84. citing Bogdin & Biklin, 2003.

[164] Benjamin, "The Storyteller: Reflections on the Works of Nikolai Leskov."

Figure 3.3 Organizational model of work in visual storytelling

a. Pre-production

In the pre-production stage my aim was to establish the collaborative nature of the project through talk. In these early meetings we sought to identify the outlines of the story arc we would craft by defining a) audience, b) story ideas and c) beginning the process of identifying potential visual ways to elucidate these points. For example, Michelle suggested during one of our pre-production meetings that she wanted animation as an element in her film. Yet my own inexperience with animation, and Michelle's lack of drawing skills, quickly led us to consider alternative ways to propel the visual narrative forward until we were able to solve this problem by having Michelle build a visual timeline of her illness narrative using autobiographical archival photographs. Pre-production meetings varied in length and included in-person meetings as well as virtual meetings.

b. Production

Production consisted of participants filming, in their own environments, elements they considered relevant to the construction of their film using their own digital SLR cameras, tablets, and smartphones. This footage was then reviewed jointly and led to the development of storyboards (see Figure 3.4) that informed our plans for team production. Team production consisted of an on-camera interview, specific visual elements we had developed in pre-

production, like Michelle's visual timeline, and the filming of additional b-roll, or supplementary footage that could be intercut with the main footage.

My goal was to produce a high-quality film using minimal equipment. For the team production day, video and audio were recorded using a Sony A6500 Alpha camera that allowed us to record HD video, a GoPro Hero5 pov camera, an H1 zoom digital audio recorder, and a RØDE smartlav microphone. This is the equipment used for our on-camera interviews.

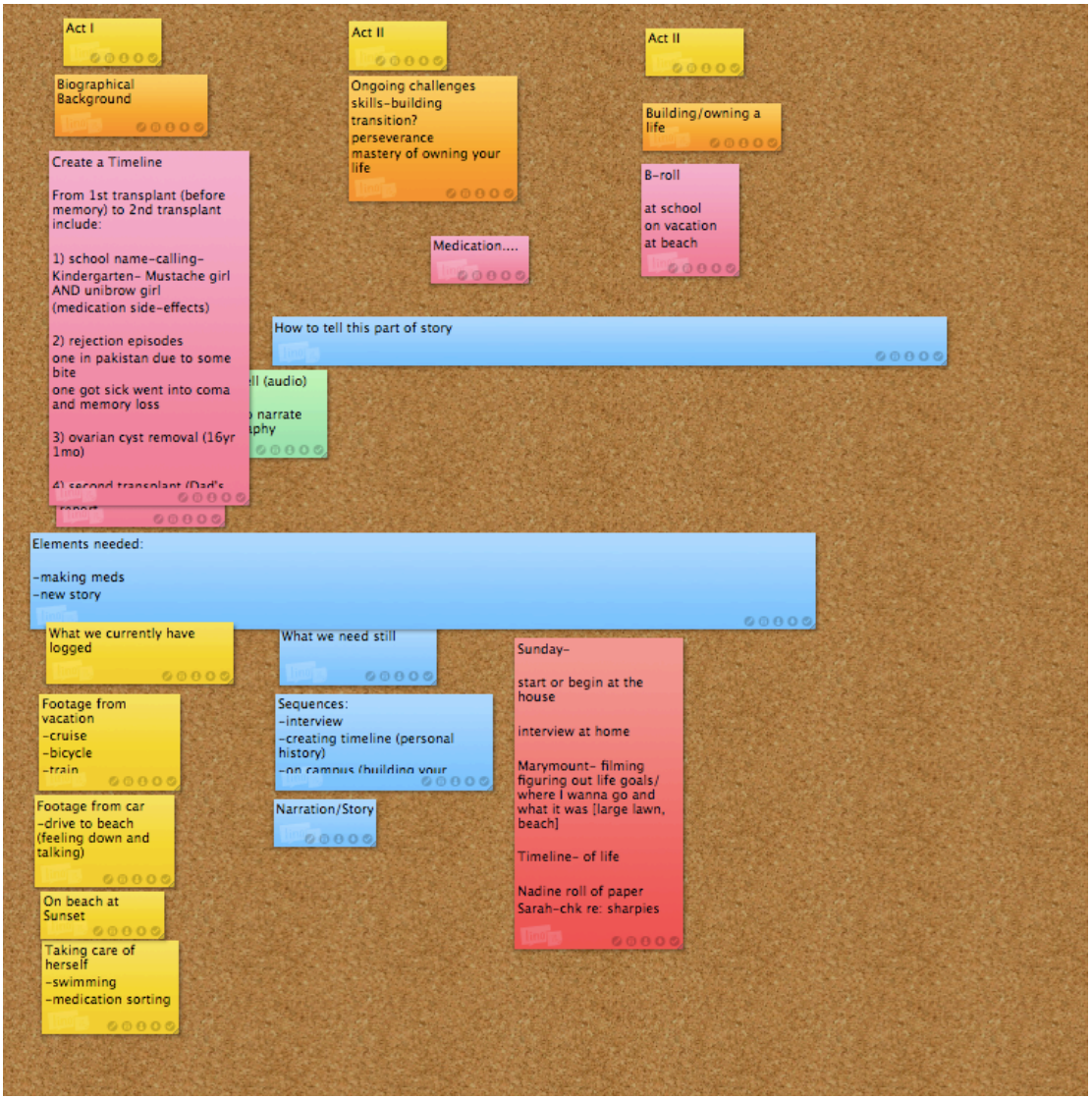

Figure 3.4 Example of a production storyboard

c. Post-production

Post-production focused on building the film with the materials we had created. Using our storyboard as baseline and transcripts from our on-camera interview a paper edit was created that led to a rough assemblage of footage using AVID, a mac-based professional software editing suite. Multiple screenings with participants, and research advisors resulted in a final film.

In terms of managing the production, this stage proved to be the most challenging for maintaining a collaborative work environment requiring careful attention and self-reflection. Although youth participants were invited into the editing room, because of logistics, time and travel challenges, most of the AVID editing was done by me with significant guidance from Glen Ebesu, a professional AVID editor who volunteered his time on this project and completed the final editing pass to ensure a professional finish.

In the post-production stage I was keenly aware of story, voice, intention, as well as the multiple discussions with participants. As an observer and participant in our research process, my work necessitated stepping forward and stepping back from the process. It demanded that I try to move between roles and perspectives as I worked hard to follow our collaboratively agreed upon storylines, while guiding the flow of visual storytelling from beginning to end. In many ways this stage of work reflects the typical role of a professional producer working at the behest of her client. In other ways, the power disparities noted earlier required keen sensitivity and I relied heavily on the framework of care to guide my actions. For example, a story beat from one the videos includes a frank discussion of mental healthcare and medication. I was extremely hesitant to include this in the final video. During production I had cautioned Michelle on divulging any mental health issues, particularly because she was set to begin a job search and the videos were meant to be public documents. Nevertheless, against my own instinct, this

story was included in the final video because, a) the videos though collaboratively constructed represented the participant's stories, not my own, and because she was an adult it was her right to determine the scope of her narrative[165] and, b) in her own work, Michelle is adamant that mental health resources are tools that have helped her and can help others. Her aim, writ large, is demystifying mental health support for transplant patients through frank discussion and this was an essential aspect to her own teaching aims for this video. Even so, her film was screened with the larger team research group for their feedback before it was considered in any final, or semi-final stage.

Data collection and analysis

The primary method of data collection was participant observation supported by audio and visual recordings of each encounter. As a participant I was both teacher and video producer, collaborator and researcher. As an observer my professional background shaped how I viewed of images and stories, even as I positioned myself as an ethnographer invested in the process of storytelling. My information sources included audio-visual recordings of case study interactions, audio-video recordings created by participants, archival photographs, fieldnotes, jottings and reflections written by participants and myself after the completion of each project, production footage, and transcripts of the multiple assemblages of each film during post-production. Production occurred at irregular intervals between 2017-2019. Recordings for the initial meeting were complicated by distance and concern for the privacy of each participant. I prioritized developing a relationship over video recording and, because our meetings often

[165] If this same issue had occurred with an adolescent participant I am unsure of how I would have negotiated this problem although I am absolutely certain that the participant, her parents and myself would have thoroughly discussed the reasoning and possible implications of such a storyline.

occurred in public spaces that did not allow for complete privacy, I worked to minimize attention and focus on building relations and setting out our informal contract.

One significant challenge encountered during the project was the cancellation of quarterly transition clinics that impacted the duration of the data collection period and the recruitment of participants. The clinics, jointly organized by the pediatric cardiology and AdHF medical teams were to be my primary opportunity to introduce this study and begin the process of recruiting participants. The cancellation of clinics posed a serious dilemma. I had hoped to complete three to five films for this study. In the end two films form the data corpus for this dissertation.

Participants can be characterized as an adolescent female and a young woman who each had received multiple heart transplants as children and were either in the process of transitioning or had just completed transitioning to adult care. Participants were recruited with the help of the Raia, Deng and the ROP&P team through extreme purposeful sampling.[166] Michelle, who had successfully completed the "handoff" from pediatric to adult transplant care, and was enrolled with the ROP&P study eagerly agreed to participate in the video research project. Maria, a 14-year old, at the early stages of medical transition, was recruited over the course of a year from initial contact and discussion to participation. Discussions occurred with both Maria and her mother. The long recruitment period does not reflect their concerns about the study, but does reflect the difficulty in recruiting participants in a commitment intensive study that occurred outside of school and clinical visit settings.

Data construction and analysis

[166] Patton, *Qualitative Evaluation and Research Methods, 2nd Ed*, 169.

The data corpus is rich, varied and robust. Still, "data" like "case study" is not an uncomplicated construct. What constitutes data to an educational ethnographer? Frederick Erickson has argued that data—in terms of both datum and pattern or theme—must be *found* and *constructed*. Data does not simply *emerge*. He argues that what we, as researchers, notice is linked to opportunity, personal history, and happenstance.[167] Moreover Erickson asserts that there is more than one way to conduct critical and rigorous research and invites others to learn and "build your own version."[168] It is an invitation I welcomed.

The process of selecting and constructing data occurred as a continuous iterative process, akin to Erickson's "progressive problem-solving." To begin, editing is educational in a very specific way. In editing you become highly attuned to listening for complete thoughts and ideas. The process of repeated listening to what is said and conveyed; what is attempted but fails; and what is attempted but remains unclear leads to the identification and recognition of mini-stories within the footage. You begin to identify stories that are whole and have a beginning, middle and end and stories that need more editorial shaping in order to feel complete. In this way, editing is itself a process of data construction and analysis.[169]

After the films were completed a different type of data construction and analysis began. This phase consisted of reviewing of the audio and visual footage collected and selecting and

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[167] Erickson, "Commentary: Demystifying Data Construction and Analysis."

[168] Erickson, 492.

[169] Although visual methodologies are increasingly used in research (e.g., as visual ethnography or as in the micro-ethnographic methodology used of Conversation Analysis), little attention has been paid to how visual data is culled and constructed in the social sciences in narrative films. Significant contributions in this direction include: Derry et al., "Conducting Video Research in the Learning Sciences"; Erickson, "The Interface between Ethnography and Microanalysis"; Erickson, "On Noticing Teacher Noticing." Film scholarship offers an alternative approach to editing: See Karen Pearlman "Editing and Cognition Beyond Continuity"; Pearlman, *Cutting Rhythms*.

transcribing specific moments that emerged as noteworthy[170] to understand the process and challenges of collaborative storytelling. Although I anticipate that the data will allow for multiple iterations of data construction and analysis, in this dissertation I am limiting my analysis to focus on teaching and learning interactions—broadly defined—in the process of creating and producing visual narratives about the experiences of growing up with a heart transplant. A second, key stage of data collection and analysis was collaborative, cogenerative inquiry[171] with participants, medical practitioners, educational researchers, anthropologists, and graduate and undergraduate students in Federica Raia's ROP&P research lab as well as the LaB interest group.[172] The insights, suggestions and interpretations developed during these sessions deeply inform this dissertation.

Citations and transcripts

Like all aspects of the research method, the ways in which data is cited and transcripts are written are highly specific to discipline and research traditions. I situate this study as an educational ethnography. Ethnography is a practice of writing culture[173] that carries the burden of its own complicit history within powerful colonizing projects. Just as Elinor Ochs argues that

[170] Here, the scholarship on teacher noticing, though usually addressing classroom mathematics learning provided a helpful frame for determining what constituted "noteworthy" events.

See: Erickson, "On Noticing Teacher Noticing"; Barnhart and van Es, "Studying Teacher Noticing"; Raia and Smith, "Practitioner's Noticing and Know-How in Multi-Activity Space of Patient Care and Teaching and Learning."

[171] Raia and Deng, *Relational Medicine*; Roth and Tobin, "Co-Generative Dialoguing and Metaloguing"; Elden and Levin, "Cogenerative Learning"; Coghlan and Brydon-Miller, "Co-Generative Learning."

[172] Both the ROP&P (Relational Ontology Phenomenology and Practice) lab and the LaB (Learning and Becoming) interest group are modeled after Charles and Candy Goodwin's exemplary research lab that allows professors and students to share and discuss multimodal research in progress.

[173] Clifford and Marcus, *Writing Culture*.

transcription is always theoretically informed,[174] I recognize that ethnography is also theoretically informed.[175] I write in conversation with these theories, as part of my practice of sense-making. In writing culture, I am not positioning young people as cultural others. The films we created are not about *their* cultural ways of being. Rather as educators, researchers, parents, and adults, *we* are also constitutive of culture and it is in the negotiation of collaborative storytelling that a space opens where differing perspectives can be situated within a common knowledge ecology. Throughout, I present the data of our collaborative storytelling practice either through narrative vignettes, which are italicized, quotations and modified baseline transcripts,[176] or more fine-grained detailed transcriptions of talk-in-interaction. I zoom in and out from fine-grained analysis to more generalized and contextually focused analysis depending on the point I want to convey. As I discussed earlier, the data and analysis was constructed iteratively over time and in conversations with others. Many disciplines use ethnographic methods and their ethical guidelines vary with regard to the use of fieldnotes in protecting confidentiality. Though the short films were designed to be part of a public project, because of the limited number of participants and following the most conservative professional guidelines, I do not cite specific fieldnotes. This also reflects the fact that the narrative vignettes reflect an iterative process of sense-making in conversation with others. In addition, with the exception of myself, all participant names are pseudonyms. Finally, this dissertation is in conversation with multiple interdisciplinary scholars, although many social scientists use in-text citations, in the humanities placing citations in footnotes is both more common and preferred for readability. This is a stylistic preference I share. In this text, I use The Chicago

[174] Ochs, "Transcription as Theory."

[175] Traweek, "Border Crossings: Narrative Strategies in Science Studies and among Physicists in Tsukuba Science City, Japan."

[176] Ochs, "Transcription as Theory," 45.

Manual of Style as my citation format. This format includes an option that allows the text to be read relatively uninterrupted by placing citations as footnotes.

Summary Conclusion to Part One.

In part one, I have introduced transition as a focal point in medical and cultural contexts involving young people who received pediatric heart transplants. I set out to articulate how certain scholarly traditions and approaches influenced and shaped the design of this dissertation. Drawing from critical disability studies, childhood studies, in/commensurability scholarship, feminist technoscience studies, narrative research, situated knowledge studies and youth participatory action research, this dissertation invokes case study, critical ethnography, critical media production studies, participant-observation, and reflexivity methods in order to examine this contemporary moment of transition, rupture, sense-making, world-building, embodied knowledge and positionality with young people who live in the frontier of a biotechnological ecosystem. I use these traditions as resources because all theories are methodologically-informed and all methods are theoretically-informed. Methods and theories are not additive constructs used to investigate a phenomena. They are assemblages, that form a prism for this investigation; a prism shaped and complicated by personal histories and attunements.

Part two, is an ethnography of learning that follows the structure of our collaborative video storytelling process from pre-production, production and post-production. Chapter Four, Stories of Collaborative Practice, focuses on the key work of pre-production, including identifying 1) story arcs, 2) intended audiences and 3) developing a visual language to show and tell a story. Chapter Five: Stories of teaching, focuses on aspects of film production and sets out to discuss the lessons each participant, including myself, sought to teach others in the

practice of visual storytelling. Chapter Six: Stories of learning, examines and reflects on the post-production process and what was learned during our collaborative work.

Part Two: An Ethnography of Learning

Chapter 4 - Pre-production: Stories, Audience, and Collaborative Practice

Introduction

This dissertation is an ethnography of learning. What can an ethnography of learning look like? Tim Ingold has a lot to say about ethnography in his essay railing against what he sees as the distorted reification of ethnography across the social sciences.[177] For Ingold, anthropological inquiry is a practice of education first and foremost. It is embedded in a commitment to participant-observation: "To observe is not to objectify; it is to attend to persons and things, to learn from them, and to follow in precept and practice."[178] Ingold asserts that ethnography reflects a relational act, one that moves "forward rather than back in time."[179] In other words, Ingold positions ethnography as an iterative practice with others. Ingold's main objection, to what he describes as a misplaced emphasis on ethnography over participant-observation, is his assertion that in its generalized use, ethnography is often transformed from a dynamic practice of learning into inert "data-gathering exercises destined to yield 'results'."[180]

Ingold's essay reflects both broader concerns about anthropological authority and practice as well as his deep commitment to participant-observation. What I glean from Ingold's essay is an insistence that ethnography reveal the "educational correspondences of real life"[181] and inform an "imagination nourished by observational engagements with the world."[182] My goal is to write an ethnography that reflects how learning and teaching unfolded in the practice

[177] Ingold, "That's Enough about Ethnography!"

[178] ibid, 386-389.

[179] ibid, 390.

[180] ibid.

[181] ibid, 393.

[182] ibid.

of collaborative storytelling. The short films that resulted from this collaboration are the results of working together, making together: sympoiesis. They are participatory action research because our hope is to inform the imagination of others through the generative act of storytelling.

In this ethnography, I invoke participant-observation as a method that attends to education as an unfolding relational practice. This ethnography of learning seeks to center the dynamic practices of teaching and learning over the course of our collaborative storytelling efforts. This study began as fieldwork—data collection—but the data collected are not a set of objective observations followed by subjective interpretation. Instead, my ethnography is embedded in the concatenated practices of participant-observation, practices linked together in a series that moved forward in time. The status and relation between participants evolved and changed as we move through our collaborative project—alternating between teacher and student, producer, director, storyteller and audience. Throughout, I try to show these multiple entanglements. My ethnography is situated, partial, embodied, and affected. It is part of my own sense-making practices. My storytelling. This ethnography traces encounters—with others, with ideas, with practices—that were shaped and experienced by, and with, others over the course of our research. By writing this ethnography I hope to convey, in part, the sensations of: *This is what it felt like. This is what I thought and struggled to make sense of. This is how decisions were made, individually and in collaboration with others.* I share this not because my experiences are exceptional, they are not. Rather, I show the educational trajectories mobilized by collaborative research to reveal learning as an ongoing activity. In these portraits of encounter I hope readers gain insight into the sense-making practices of young people offered the opportunity to tell their stories outside the walls of a clinical setting. I hope readers recognize young people as knowledgeable participants, as storytellers, teachers and students.

Moreover, I seek to highlight how our collaboration was built from the ground up. How our common goals, amongst a diverse set of mutual and individual aims, enabled a productive collaboration. In writing this ethnography, I seek to highlight the negotiations, the (mis)communications, the educational arcs, and the "welter of the everyday[183]" that reflect the challenges and possibilities of learning as a way of life.

This ethnography is organized by our workflow from pre-production to production and post-production. Although each stage is often characterized as distinct aspects of filmmaking (see Figure 4.1), in reality visual storytelling is iterative. With each progressive stage we invariably step back, reassess, and rework in order to move forward.

[183] Davis, *The Return of Martin Guerre*, 4.

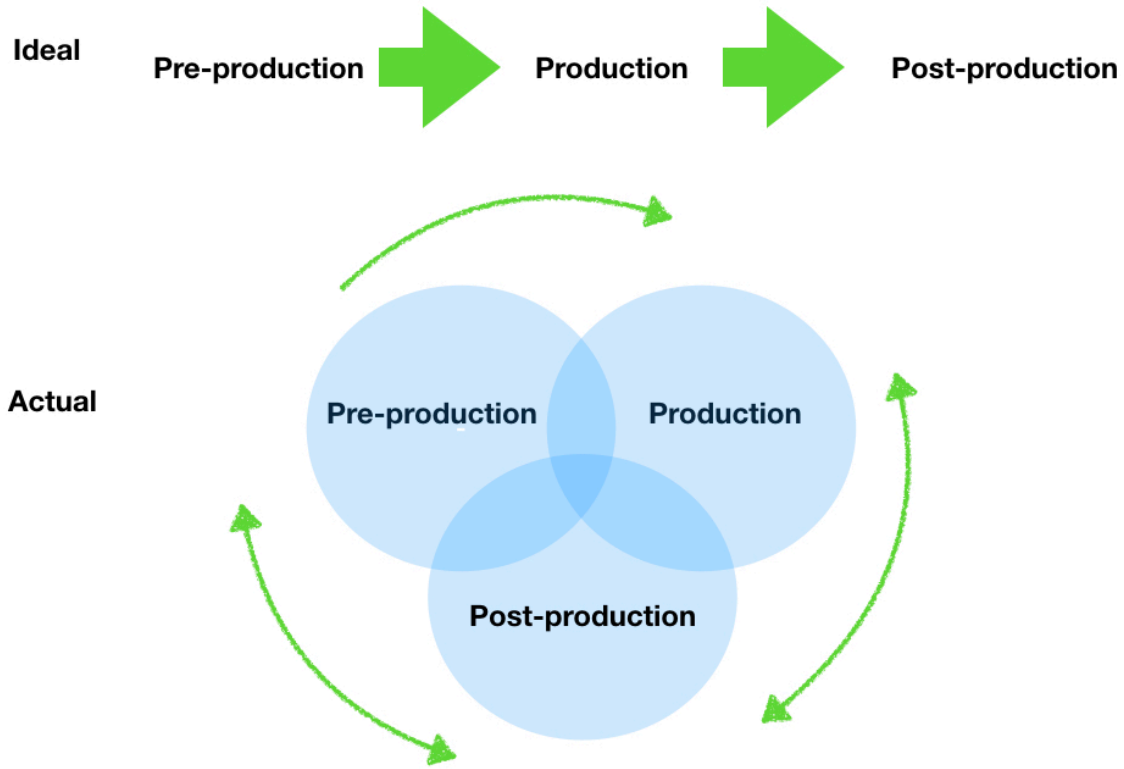

Figure 4.1 Video Storytelling Workflow: idealized and actual

Pre-production

This chapter highlights the work of pre-production in collaborative storytelling. The pre-production process involved several meetings with each participant. Some of these meetings occurred virtually, but when possible, face-to-face meetings were sought. During pre-production our goals included identifying storylines and identifying our audience while we built a collaborative practice. In doing so we sought to discover and develop narrative threads that could become key story ideas. In this chapter I discuss a first pre-production meeting as an exemplar to show the challenges of collaboration between participants with different

experiences and skill sets. I recorded this meeting and use baseline transcripts our this meeting throughout this chapter. Finally, I show how one of our critical goals—the identification of our audience—evolved over multiple interactions. Though the ideal audience may vary from the actual audience that discovers our stories, I discuss how the challenges of determining and identifying whom we hoped to speak to, reveal how we established and nurtured a collaborative storytelling relationship.

Beginnings

I first met Michelle during preliminary fieldwork in a hospital at a newly established transition clinic meeting for adolescent and young adult heart transplant recipients. Michelle was asked to participate, to share her experiences of transition with patients and families gathered that morning. After the clinic, when I asked Michelle if she would be interested in participating in my storytelling project, she jumped at the opportunity, telling me that she was willing to work on any research project that focuses on heart transplant recipients. Michelle's readiness to participate reflects, in part, her own struggles to recruit research participants for her undergraduate capstone project. Her difficulty had delayed her graduation, and so her participation in this study reflects both an interest in the subject of transition as well as an interest, engagement and experience with research. For our first pre-production meeting I ask Michelle to think about the stories she wanted to share, lessons she wanted to teach about transition, and we set a time for our meeting.

When we do meet Michelle and I are both eager to start our work together. As I set up my recording equipment, Michelle begins sharing story ideas. From the outset it feels as if Michelle is unleashing a floodgate of pent-up thoughts and experiences. She shares her fear, love, frustration, care, anger and indebtedness—emotions that color the memories of childhood

and shape the stories she wants to tell. Her speech tumbles out, moving from topic to topic, as if she is just recalling it, as if the memories are readily accessible waiting to come to the fore. There is a sense that she has so much to convey and has had only a limited opportunity to share it. She shares her experiences of becoming aware that her heart transplant was uncommon—that it conveyed upon her a special status and responsibility—unusual among other children in her school. She tells the story of multiple health scares, the damage that her medication inflicted upon her body, her physical appearance and her mood.

These narrative threads culminate in the story of her second heart transplant and the necessity of a kidney transplant. She shares excruciating stories of temporary paralysis and sudden health scares that reflect her experiences of growing up aware that death is a part of life. At one point, Michelle's speech peters off and she apologizes to me, sensing perhaps how overwhelming her talk has been.

Michelle is 25 years old when we meet. She lives with her parents in her childhood home. Though she initially struggled academically, especially as undergraduate, Michelle has successfully learned to navigate college and is currently enrolled in a graduate program in clinical psychology. She aspires to work with other transplant patients in hospital environments and sees her participation in this study as fulfilling part of her life mission. Though Michelle she has already successfully transitioned from pediatric to adult medical care when we meet, she describes her transition as extending long past the actual "handoff"[184] from the pediatric to the adult cardiology transplant team. Her experiences of growing up with a transplant and the challenges of transitioning to adult care linger with her and shape her career aspirations. Her experiences are sensitive, emotive, and powerful. When she shares them with me they feel

[184] Handoff is the term used colloquially by the medical teams to mark the transition of a patient from one team to another. In some studies "transition" refers to this single act of patient transfer. However, the pediatric team uses "transition" to describe a more gradual process of becoming an adult.

untamed. Though primed for storytelling, Michelle has not yet narrativized her experiences. By this I mean that though it is clear from the outset that Michelle has thought a lot about her experiences, her narrative does not follow in a linear fashion or other standard formula. In our initial meeting and often thereafter, Michelle's experiences spill out of her, run over me, as she recounts her complicated illness history punctuated by hospitalizations and medical and personal challenges. She shares memories of moving in and out of schools, of having to learn how to cope with bullying that she ascribes to the side effects of medication that impacted her physical appearance. These recollections spring forward and leave me, the listener, trying to stitch these threads together, organize them temporally. I wonder, now in reflection, if my experience in these initial encounters can be likened to the difference Walter Benjamin invokes between information and storytelling, where I, as a listener, am bombarded by information that has not been processed to travel from one person to another. [185] I am also keenly aware that although Michelle says she is focusing primarily on the relationships with her medical team, her narratives are also complicated by the fact that looming underneath and layering Michelle's medical history is her own struggle to negotiate many transitions including the transition to adulthood as a first-generation, modern American woman devoted to her family just as she is the beloved, protected daughter in a traditional South Asian Muslim family. It is only when, in the midst of our talk, Michelle tells me, "I'm trying to fix things," that I begin to find a pattern in Michelle's narrative threads. Her statement becomes an anchor for me from which the possibility of our collaborative practice begins to emerge.

Telling Stories

[185] Benjamin, "The Storyteller: Reflections on the Works of Nikolai Leskov," 89.

Michelle is clear in her intention. She says that she is "trying to fix things." What her statement teaches me is that Michelle is primed for storytelling with an audience in mind and a lesson to teach. She wants to "fix things." She elaborates:

> "I want health professionals to know being a transplanted person that has lived my entire life with a transplant versus [a person who] had to transition from normal life to transplant life isn't that different from being like anybody else. I've made mistakes and learned from them."

As I listen back to the audio recording I note the depth and thoughtfulness in the information Michelle shares. She maps her recognition of difference, of a distinction between "transplant life" and "normal life" even as she immediately begins to blur those differences: it "isn't that different from being like anybody else." Transplant life and normal life are distinct, but they are not *that* different. How to live within this state of difference, of in-betweenness, becomes a repeated question and practice during our research.

Through her speech Michelle is also delineating another kind of difference, one that differentiates her experience of transplant life from others, namely patients who receive their first heart transplant as adults then have to transition from normal living to transplant living. Michelle was first transplanted at 18 months old and has grown up knowing no "other way" of life. For Michelle, transplant life is normal life and like others living their normal lives, she has made mistakes and has had to learn from them. This is the lesson that she wants to impress upon healthcare professionals. Despite her exceptional life experiences, Michelle wants to be seen and treated as a normal person.

Here, and in our meetings thereafter Michelle is insistent: seeing, treating,

speaking to the patient as a whole person is an essential and missing practice in healthcare:

> The patient isn't a patient, the patient is a person...The person has feelings. The person even though they hit the eighteen mark and is supposed to be an adult now, has attachments. Yeah separation, this and that and you need to learn to let go and all that, yeah I like I understand that, but being able to connect with somebody beyond that type of level and knowing that you are so sick and they saw you through your whole entire sickness. They were there for you. Making sure nothing happened. Just knowing that your head doctors are gonna kill anyone that does anything to you. That [she laughs] is everything.

What I note in this exchange is the aftermath of precarity— of having to confront life and death, and not being in control. Michelle's precarity is reflected in her sense of being beholden to, thankful for, her lead doctors when she was "so sick." Michelle's sense of indebtedness extends beyond her doctors to her heart donors. She tells me she is living for three people: herself and well as her two organ donors whose very death have enabled her life.

Indebtedness is a common theme in transplant literature exacerbated by standard metaphors that describe donor hearts as "gifts of life" neglecting the cultural and psychological complexity entailed in the accepting and receiving of a gift of life.[186] Repeatedly I hear young people refer to their graft hearts as "gifts of life" and each of these references conveys the symbolic significance that donated organs are gifts that can never be fully repaid. Symbolic debt

[186] Though the literature on the complexity gift exchange in organ transplantation is rich, especially in the fields of medical anthropology (see: Scheper-Hughes, "The Tyranny of the Gift."), social geography (see: Sothern and Dickinson, "Repaying the Gift of Life."), and nursing (see Sque and Payne, "Gift Exchange Theory: A Critique in Relation to Organ Transplantation"; Vernale and Packard, "Organ Donation as Gift Exchange"; Siminoff and Chillag, "The Fallacy of the 'Gift of Life'"; Drew, Stoeckle, and Billings, "Tips, Status and Sacrifice."), in my limited observation of clinical practice talk involving organ transplants as gifts of life are more direct and far less nuanced.

has manifest implications too—during fieldwork one young man currently hospitalized mentions his discomfort at how a donor family places expectations upon him to be more like their sport-loving son. This is conveyed to his doctor by a nurse transplant coordinator, signaling an important task. The doctor says he'll come back later to "re-frame," re-cast the narrative of obligation to his patient. Margrit Shildrick, whose work examines the impact of heart transplantation on adult patients, frames transplantation as a process of incorporation. Her work problematizes the 'gift of life' metaphor and argues for a corporeal ethics that situates the incorporation of otherness not as unique to transplant patients, but as *the* condition of (person) subjecthood.[187]

Attending to stories

To tell a story from the position of indebtedness, of lacking, is to presuppose a burden: the necessity that one's life be worthy, one's story be worthy for others to listen. Michelle announces her intention from the start. She seeks to "fix things." Yet how her narrative will unfold is still, at this stage, unknown to her. Therefore, it makes sense to me that in this first attempt to describe to a new interlocutor (me), Michelle conveys a tentativeness—the exploratory beginning of narrative threads rather than a well-rehearsed voice of a storyteller who knows the path her story will take. In re-listening to our conversation I notice Michelle speaking from a fractured perspective, not a place of uninhabitability, but certainly a de-centered position. She speaks of "the patient" not of herself, even as she asserts her rights as a person:

"The person has feelings

[187] See: "Hospitality and 'the Gift of Life': Reconfiguring the Other in Heart Transplantation"; "Disrupting Hybrid Bodies"; "Messy Entanglements."

The person…has attachments."

Even as it is apparent to each of us that "the person" in Michelle's speech is Michelle herself, even as Michelle begins to characterize the patient's world as her own ("they hit 18, [and are] supposed to be an adult, etc."), the disconnect between story and storyteller persists leading to the position of indebtedness, gratefulness and the recognition of the extent to which others have cared for her. "That," she says, "is everything."

Existential debt propels Michelle's narrative thread forward. I wonder if her desire to fix things reflects an attempt to settle the debt, for it is from empathy and experience towards a position of profound existential vulnerability that Michelle asserts the need of patients to be recognized, treated, cared for, as individuals first and foremost.

I also note the internal tension involved in forging an adult identity despite the burden of debt. This tension is made explicit when Michelle describes how her relationship to her adult team differs from her relationship to her pediatric team. Because Michelle has grown up within the institution of medicine, and because her status requires continual monitoring to ensure her graft heart is performing optimally, the relationships Michelle developed with her medical team, extend beyond cursory office visits more common to my own healthcare visits. Michelle tells me about one doctor who, during an office visit when she was sixteen years old, took her new BMW for a test drive. She explains,

> "Dr. P was the coolest guy. He's like, 'that is such an awesome car, I want to drive it.' So I always made that connection with him. He was the one that had serious, serious talks with me. The one that [told me], "If you don't take your meds, you're gonna get sick and you're gonna end up in the hospital.
>
> If you race in your car, you're gonna waste the heart that we gave you.
>
> It is a present. Do you want to waste the present? No? Alright then, knock it off."

Michelle ends by reflecting:

> "Having a doctor that has always been someone that I admire and always wanted to look up to...don't get me wrong, I love my adult team but my peds team is my life."

The bond Michelle feels toward her pediatric team is understandable. They are a source of childhood comfort running through Michelle's tales of terror, uncertainty and concern. Yet, even in this short anecdote, it is apparent how complex caring—as a noun and verb that describes a relationship, a practice, and regard—has been in her life. Through this anecdote, we see care as a reciprocal and unequal concern between the adolescent Michelle and her pediatric doctor. I also note how Michelle's regard seems timeless and wonder if her doctor feels the same. We see how her medical care goes beyond an institutionalized sense of concern, one that seems almost, at times, parental.[188] We also see how care is defined to Michelle, by a doctor she admires, as an obligation that Michelle has toward her transplanted organ: "Do you want to waste the present?"

I see in this othering of Michelle's heart, this talk of her heart as a gift distinct and separate from Michelle herself, as a form of deflection, a desire to impress upon Michelle the consequences and dangers of her actions (racing her new car, not taking her meds) that place her life in risk. Yet Dr. P's discussion of illness and death takes place under the guise of a present, a social and cultural gift that underlines her obligation as a recipient. No wonder then, that Michelle's own storytelling mimics this deflection: *the present, the patient, the person.* She has learned and been taught to make these distinctions. I also note the extent to which Michelle has been taken care of, treated like

[188] During fieldwork a pediatric cardiologist described his relationships with his patients as straddling the boundary between familial and professional responsibilities. This was a position he both valued and sought to negotiate responsibly.

an individual by her doctors. It is evident in the car test drive, in her gratefulness towards her lead doctors, and the remembrance of their worried faces in moments of crisis. Nevertheless the overall experience of being objectified, of being positioned as "the patient" within the institution of medicine is one that chafes and propels Michelle's participation in this collaborative storytelling project.

Throughout our first meeting, a subtext pervades. I listen and Michelle teaches me about growing up with a chronic condition. Michelle tells me how, after her transition, she returned to her pediatric doctor in order to ask him to do a biopsy that is part of her normative, continuing care:

> "I went up to him and I asked him…I know you're not supposed to do it, I'm supposed to grow up and go away, and be blah, blah, blah, but I want you to do my biopsy.
>
> And he started laughing, he's like "you're never gonna grow up."
>
> And I'm like 'k' do my biopsy."

Michelle has a sense of what it means to be an adult, what it means to grow up, but it is a projection defined through the negative. She has not lived up to her vision of adulthood, yet she operationalizes this lack in order to get what she wants: "'k' do my biopsy."

Even as Michelle has a clear vision of what she wants to convey—"I want to fix things," the jumble of lived experiences results in tales rich in momentary detail but lacking a connective thread, or emplotment.[189] Repeatedly, I find myself interrupting Michelle asking her to clarify so that I can follow, and in the process, I discipline her tale. These exchanges highlight a critical

[189] Ricoeur, *Time and Narrative*.

task of collaborative storytelling. Both Ochs & Capps [190] and Raia through Bakhtin[191] discuss the dialogic aspects of storytelling that are marked by co-telling along a continuum of low to high activity. In this research, co-telling is an essential activity, but co-telling requires a prior relationship, one that Michelle and I are only now, at this stage of pre-production, beginning to establish. In these initial meetings telling, listening and unraveling the messiness of lived experience in a quest to discover narrative threads we want to explore together subsume the activity of co-telling. This too, is a powerful dynamic that must be negotiated carefully in our collaboration. In my effort to clarify, to follow Michelle's narrative threads, it is essential not to close off the beginning of stories, to allow multiple narratives to unfold. I have offered Michelle the opportunity to share any story she thinks is important, any lesson she wants to impart. These are her stories and her priorities. Yet in listening back to our encounters, I flinch at the number of times I interrupt and forestall Michelle in the act of telling. In practice, because I have prioritized my own efforts of sense-making, I hamper Michelle in the very act of discovering and sharing her narrative trajectories. I take this as an important lesson for future collaborative research. As important and crucial as co-telling will become, listening as an activity of learning, teaching and sense-making is equally critical to our collaboration. To be productive, our work must focus on identifying and mapping out the possible narrative arcs our short film will trace with less regard, at this stage, to the fuller shape or trajectory of the tale. My collaborative goal lies in helping Michelle transform her intent into a coherent story, a visual whole.

A question of audience

[190] *Living Narrative*.

[191] Raia, "Practices of Care."

In our first meeting Michelle is clear that her ideal audience consists of healthcare professionals. As a listener and co-teller, I am ambivalent with her choice at this stage of our work, unable to envision a narrative whose sole purpose is overt critique. My ambivalence comes from several stances: for one, I do not know how effective a 10 minute film can be if our main purpose is telling others what they do wrong. I am also aware that Michelle's critique comes from the perspective of a patient, and wonder how the unequal status between patients and healthcare professionals will impact how her message is received. My experience as a producer has taught me that films are more effective when you show rather than tell audiences what to think. My stance as an educator leads me to believe that though Michelle's objective is clear, our lesson planning is still at a nascent stage. Still, I do not share my ambivalence and my silence allows a determination of audience to remain open even as Michelle continues to develop story ideas and we continue to develop our collaborative relationship.

Multiple Audiences, Multiple Narrative Threads

As Michelle and I continue to meet and discuss our film, her ideal audience continues to evolve, expanding and contracting at times, changing from healthcare professionals, to parents, to herself and to other heart transplant recipients depending upon her narrative intent. The visual storytelling project is structured relationally—it looks outward in the hopes of addressing an audience and in doing so the films participate in community building. They are also relationally structured inward, toward each participant in the collaborative process and in doing so, they participate in an ethos and logic of care.[192] One of the striking aspects of our developing collaborative practice is the extent to which the mediation and negotiation of flexible positionalities, expertise, and storytelling approaches is required throughout the pre-production

[192] Garro, "Enacting Ethos, Enacting Health"; Mol, *The Logic of Care*; Noddings, "Caring."

process as narrative threads emerge to be woven into the story, emerge to be stranded outside the narrative whole, or are transformed in the process of storytelling. Just as we are discovering and shaping a narrative we are also negotiating the ethics of collaboration. We navigate working together and story work simultaneously. The trajectory of work can be seen, in part, by tracking the multiple intended audiences that emerge as Michelle's narrative unfolds across three different encounters. In these excerpts, the iterative practices of collaborative storytelling are seen. They are scenes from storytelling in-the-process-of becoming. The first except is culled from our first pre-production meeting:

Excerpt 1:

Michelle	I would want mental health professional to know, I mean well professionals to know, being a transplanted person that has lived my entire life with a transplant versus had to transition from normal life to transplant life...
Me	mhmm
Michelle	...being a transplant isn't that different than being with, like anybody else

The audience for Michelle's initial story idea is clear: she is speaking to healthcare professionals. Although Michelle makes a correction from "mental health professionals" to "professionals" early in her speech, my understanding is that this correction is not meant to obscure mental health as her concern. Rather, Michelle's correction accurately reflects Michelle's intended audience of mental health professionals as well as other healthcare professionals. Michelle is a mental health advocate. This is part of her graduate professional training. It encompasses her vision of her professional future. In our discussions and in our film Michelle consistently makes a case for de-stigmatizing mental healthcare. What she wants mental health and other healthcare

professionals to know is that despite her exceptional patient status as a transplanted person, she is not "that different" from anybody else.

In our first pre-production meeting Michelle identifies an audience and a story to tell. Yet her decision, so clear during this encounter, continues to expand throughout pre-production. In our work together, in my solicitations and in Michelle's crafting of her narrative, Michelle's intended audience begins to expand change.

The second excerpt comes later in our process as pre-production is shifting toward production. Here, Michelle has been tasked with filming elements to be included into our visual narrative. At 18 minutes and 24 seconds, this sequence is the longest clip created by a participant in this study. Michelle records this video while she is alone, driving in her car. It begins as Michelle is selecting an Indian song that begins to play loudly. Michelle drives and dances to the music before turning it down to begin her story. Even in this clip, elements of Michelle's storytelling practices can be seen. Michelle creates a context from which to begin her narrative. She sets the stage with exuberant music and dance before she settles in to tell her tale.

Michelle begins by recounting her previous day when a series of cascading events leaves her frustrated and depressed searching for a way forward: "I had an interesting, fun-filled day of thinking I was having a heart attack." Michelle's juxtaposition of fun and heart attack, clue me in to her bitter mood. Michelle has contacted one of her doctors who assures her that her heart and kidneys are healthy, but during her phone consultation raises the possibility of a lung infection. This possible setback opens a vortex of medical uncertainty that calls into question all others aspects of Michelle's life. She continues:

I don't like uncertainty. I'm supposed to be in class.

I called my friend and told her I'm in the ER…which I'm clearly not.

If this were only a narrative we could appreciate Michelle's traditional storytelling structure. Michelle quickly establishes a context and a crisis to be resolved. But this is not simply another story, this is uniquely Michelle's and as uncertainty swirls around her Michelle unleashes her frustration through storytelling. Michelle moves to the main subject of her talk:

Excerpt 2a:

Michelle I just really, I just really don't know what to do with myself anymore.

I want to do well in school.

I wanna...I wanna succeed and accomplish all my goals.

[yawns]

But mostly I'm just tired. I'm tired of chasing the dream when I always get nothing done in the end.

Michelle's story is a tale told to her camera, shared with me. When Michelle gives me this clip we sit and watch it together. I am moved, concerned, confused, and uncertain as I cycle through my roles as producer, teacher, collaborator, and researcher. I do not know how or if Michelle is intending this clip to fit within our storytelling project. I know that it is important that she shares this information with me. As I struggle to make sense of the footage, I come to believe that the audience for this story is ultimately Michelle. In our initial joint viewing, I ask Michelle to help me make sense of it, of how she envisions this sequence within our collaborative film. Michelle is also uncertain, knowing only innately that this clip is important. She describes this sequence, multiple times, in the video and in our joint viewing as a rant. Her overt story traces a possible health crisis that escalates to an existential crisis: "I don’t know what to do with myself anymore." At this point Michelle begins to elaborate adding insight to her uncertainty:

Excerpt 2b:

Michelle: I am embarrassed to say that my dad believes I should only stay in the local area, not to dream big about

[in breath]

about working in UCLA, and uh, staying close to UCLA and he even he even stated that I should just quit school, stay at home and be a home body, what like girls should be. Obviously I got furious, but I, I was more furious that I was disappointed. Not so much as you know, sad about what he said. I put my dad on the highest pedestal and when he says these things, when he says these things,

[yawns]

I get more hurt than he could ever imagine.

[The camera sitting atop her dashboard begins to fall off as Michelle reorients it while continuing to drive]

Why? I have given up on him ever supporting any of my decisions.

Michelle is wounded by her father's cultural, gendered and limited vision of her life and future. She shares his implicit criticism of her participation in our research. Michelle continues contrasting his goals for her, with his goals for her older brother for whom he wants success and independence (a goal Michelle says her brother does not share). But Michelle *is* driven by a desire for success and independence and keenly disappointed in herself:

Excerpt 2c:

Michelle I am ranting because I am angry, because even though I know I have no self-control of my life, I have made it a mission to self-sabotage myself every time everything is going good for me

[yawns]

I fall off the wagon again. I'm disappointed in myself and I prove my parents are right that I will not amount to anything.

In our discussions, Michelle has shared examples of "self-sabotage" that include skipping class, not following through on assignments, etc. However, there is one example that raises alarms and helps me contextualize her self-criticism within the context of this clip. Michelle, in spending time with her friends, has been going to Hookah lounges—bars that specialize in the communal smoking of flavored tobacco passed through water-pipes. I believe this is one of the "mistakes" she refers to in our earliest conversation. She knows that by smoking she is endangering her own precarious health and that her actions may have precipitated her current health crisis. In addition, what I note in watching this clip is that, in this excerpt and throughout this sequence, Michelle yawns frequently and acutely. At times her words seem slurred. I do not know if this is a symptom of extreme exhausting, a physical reaction to her current crisis or a combination of both or neither. Either way I am alarmed that she is driving and recording in her current state.

During my first viewing of this video, sitting and watching this sequence next to Michelle, I flag several concerns. Our discussion provides a glimpse into our research relationship, how it was structured and negotiated at this stage of our collaboration. First, as a teacher, researcher and producer, I am acutely concerned about Michelle's safety and immediately ask her never to drive and film herself again unless her camera is securely mounted in her car. I show her several examples of inexpensive, but specialized mounting equipment she could purchase. This becomes an absolute and overt rule for future recordings. In addition, I am concerned about Michelle's driving while exhausted, as well as her experimentation with smoking and its impact on her health. These concerns do not stem from

my position as co-teller, rather they are concerns that grow out of our collaborative relationship. In both instances, Michelle is clear. Her actions are her business. She has close friends watching over her health. Her choices are hers, not mine, to make. Michelle is keenly attuned to any stance I might take that could be perceived as a form of surveillance or an exercise of authority. Even though my concern is part of a relationship of care—toward Michelle as a person, toward my responsibility as a researcher, teacher, and producer—Michelle is clear in negotiating her terms for collaborative research. She wants me to see the flawed, whole person she is, the person in transition, struggling with uncertainty, struggling to gain self-control of her life, without my intervention. Even as our research and teaching relationship evolves to include friendship, our roles and responsibilities require mutual negotiation. Later in post-production, when Michelle begins cancelling several meetings at the last minute, another sort of negotiation will be required. Our relational framework is continuously pulled and pushed in different directions throughout our collaboration and it is ultimately our attention to power relations as well as our flexibility in adjusting to the needs and responsibilities we have to one another that allow for the successful completion of our storytelling project.

At this point in our joint viewing the question of audience that began our discussion of Michelle's clip is still uncertain. After mentioning her self-sabotaging tendencies, and that she does not wish to live down to her father's expectations, a narrative turn begins to take place. Instead of seeing her life through a lens of disappointment and failure, Michelle begins to articulate a different vision of her future. One inhabited by her hopes and dreams.

Excerpt 2d:

Michelle The world sucks ass right now, but maybe the universe is looking for a leader to say, "hey, the world sucks, let me contribute."

> Let me contribute to the bare minimum of what I have in my capability and in my scope of practice.

Here, Michelle finds a way to reposition herself as a potential leader, as a knowledgeable contributor. The clip continues with Michelle listing her educational accomplishments culminating in her work towards a Masters in Clinical Psychology with an emphasis on Marriage and Family therapy. Even as she lists her accomplishments, her narrative of self-critique continues with Michelle noting ways she can become better educated and more attentive to self-care by driving and listening to music.

The overt story is, as Michelle acknowledges, a rant. Michelle describes a crisis and its complicating factors including the loneliness of having dreams and goals without familial emotional support. Although I recognize the importance of this sequence immediately, I also recognize that it is not necessarily part of a lesson plan for the audience of our film. Neither am I the principal interlocutor for this tale. Rather, my sense of this narrative clip is to situate it as part of the practice of collaborative storytelling. My role is positioned, in this moment, as an audience for Michelle's story. In my work of listening and sense-making, Michelle creates a space where she too can be an audience to her story. Her narrative highlights the complications of transitioning to adulthood and the challenges of living with ongoing health precarity. The rant becomes an occasion for Michelle to vent her frustration and discover alternative ways to envision a livable future.

If I am not the principal audience, I certainly note significant subtexts in this sequence that inform our collaborative process. In this emotional, raw, and brave recording, Michelle speaks about her desire to contribute to the world. She says, "I wish I was, there was, a way I could help somebody," and later in the video clip, "There's so much in my head that I want to

say. But no words to say it." In reflecting on Michelle's expressions of her goals and her inadequacies, over time and through our interactions, I realize that my goal is to be a catalyst, to help Michelle discover the ways her story might help others; to assist Michelle in finding the words to express her unique experiences and perspectives in ways that participate in an practice of caring for and with others.

The audience for Michelle's video continues to transform long into the production and post-production process. It is only when we are shooting in our final day of production that another of Michelle's intended video audience begins to crystalize.

Excerpt 3:

Me So here's what I want you to think about and you can do several different reasons, maybe, like what would you hope is accomplished with this video...

Like who do you want it to see it and what do you want them to understand or convey. What's important to you?

Michelle With this video I hope that people are able to...

(pauses 3.9 seconds)

With this video I want people either post transplant, pre-transplant, considering a transplant—having to go to the doctor's appointments and all that stuff—I want them to know that it is hard. It's not easy.

What I note in this exchange is the extent to which our relationship has evolved. I am now an active participant in shaping and crafting Michelle's narrative. As I work to elicit a statement of purpose, Michelle makes explicit another audience that has motivated her participation in this research from the start: other transitioning heart transplant patients. From our earliest story meetings to this final day of filming, the overt audience for Michelle's story has continually evolved and expanded. Her narrative is able to encompass not only healthcare professionals, not only the two of us, but also other potential and current transplant recipients. These changes occur in interaction over time. It reflects a crystallization of audience as her narrative threads come to be realized, knitted together, through the act of storytelling.

Building a collaborative practice

At the start of our working relationship what connected Michelle and I was only our mutual research interest in the lives and stories of heart transplant recipients and our willingness to listen and learn from one another. Our first encounter [see excerpt 1 and Figure 4.2] reflects our initial efforts to engage in collaborative work from positions of difference:

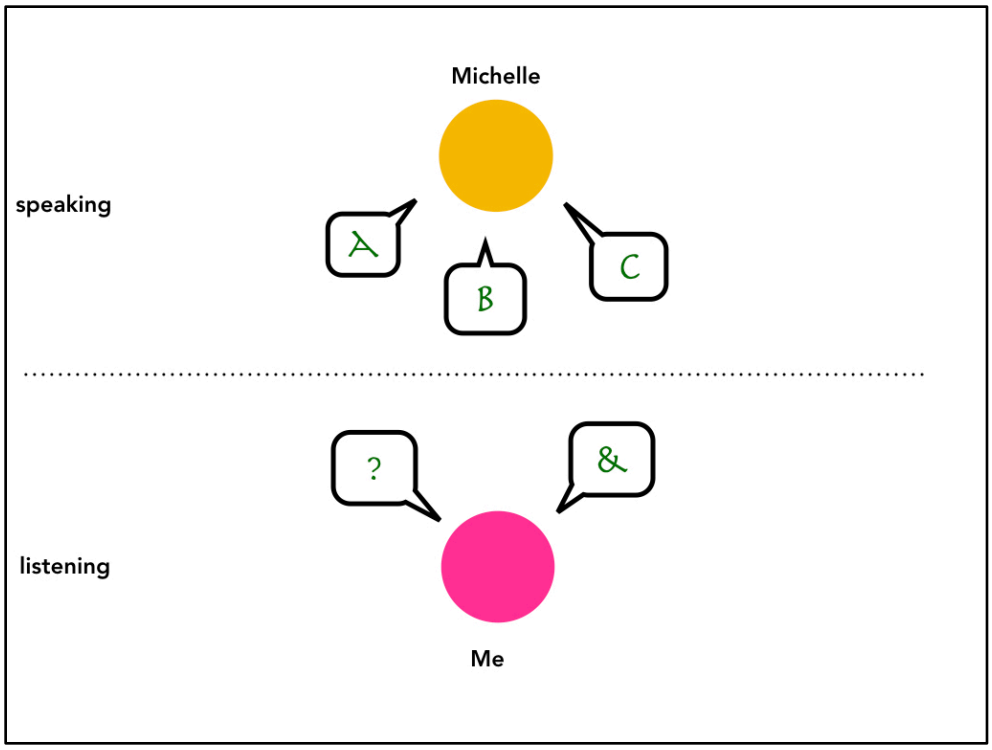

Figure 4.2 Initial working relationship

In our first pre-production meeting Michelle teaches me about her experiences of growing up with a heart transplant. She moves from topic to topic (represented as "A," "B," "C") sharing a wealth of ideas and narrative threads. In this encounter I am a listener, the recipient of information and a cataloger of potential story trajectories (represented by "?," "&"). We work together but distinctly, tentatively building our relationship. Michelle lays out the lesson she wishes to teach. It is clear, and authoritative. She wants health professionals to recognize and treat patients as individuals. Though her goal is singular, her stories are intricate, layered, embedded in experiences of precarity, care, obligation and love. In my role, I struggle to identify potential narrative arcs, define ways in which I can assist Michelle realize her storytelling goals.

By the time Michelle shares her "driving" clip [Excerpt 2a-d] we have met several times and our working relationship has evolved to one of cautious trust and respect. Michelle's storytelling practices have changed too as her role in this project develops. In the clip Michelle is the sole speaker presenting a story to a camera. While driving she sets the mood through music and dance—all practices she identifies as part of her self-care within the video. This context enables her to speak, to share her frustrations and uncertainties about her health even as she articulates a vision for her future.

As we watch this clip together, I wonder about the audience and the objective of her recording. Michelle has been tasked with filming sequences for our collaborative video. Yet when we view this clip together we are both circumspect, each acknowledging the importance of the story, but hesitant about its use. My initial reaction is to assume, what I believe is, an authoritative, caring stance: myself as a responsible adult, teacher, producer, and researcher. Yet Michelle is very clear in rejecting this move. As I struggle to make sense of this clip and our interaction, I come to realize my role in this encounter. Michelle is sharing a moment of profound vulnerability and uncertainty. She shares this with me, not as a call for help, a gesture for me to assume authority. Rather she is presenting a narrative puzzle, asking me to collaborate with her in making sense of the recording. In watching and listening to the clip together we each recognize that this story is important. Yet neither of us can articulate why. Only in reflection do I come to understand that it is our joint viewership that is critical (see Figure 4.3). By viewing this clip with me, Michelle is able to see her story from the position of an audience, an outsider. As we puzzle making sense of the recording within the context of our collaborative work, Michelle is able to recognize her role as a storyteller, a teacher, and filmmaker just as I begin to define my role in helping Michelle develop her story arcs. We are no longer separate individuals grappling to communicate to one another. Instead, we have

positioned ourselves as collaborative listeners, making sense of stories, of our roles, and of the place of storytelling incrementally and together.

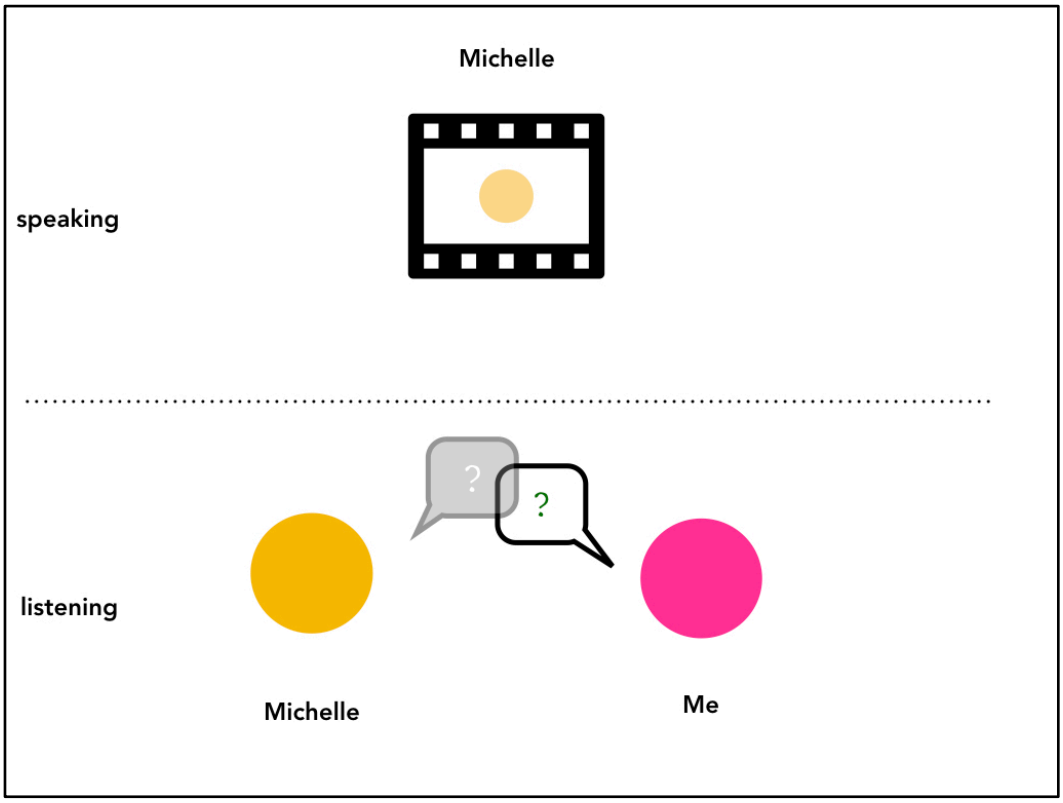

Figure 4.3 Collaborative listening

As our work progresses and moves from pre-production to production, I have worked to keep the question of audience open, delay the final decision. This open stance allows us to stay flexible and attentive as we discuss and begin to translate multiple narrative threads into visual storylines. Our decision on ideal audience remains unresolved until our final day of filming. In Excerpt 3, I push Michelle to choose. I ask her, "What's important to you?" Michelle's response, "With this video..." is a performative response. She knows that her answer is crucial to our film, that it will be included as part of our visual story.

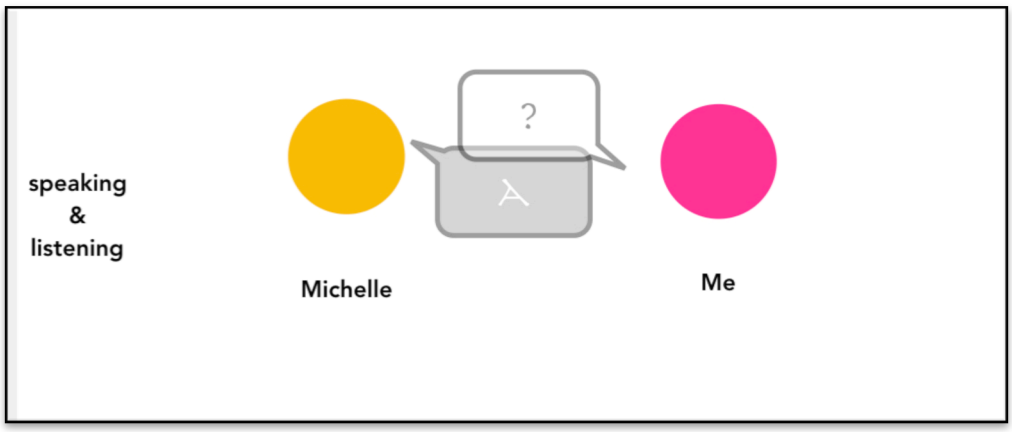

Figure 4.4 Collaborative storytelling

What this interaction shows is a collaborative relationship that has matured. We are now co-tellers in our narrative short, working together to build a cohesive video narrative (Figure 4.4). The narrative is still Michelle's. It is her lesson plan, her ideal audience. But now our roles have evolved so that we are no longer individuals struggling to make sense of each other. We are now on the same side of the problem, with a mutual research and story agenda. By the time we identify the ideal audience for our narrative we have built a collaborative practice, learned how to work together to complete our narrative film.

In the next chapter I move from the work of discovery, exemplified in pre-production by decisions regarding story ideas and audience, to the work of production and translating our narrative ideas into a visual whole.

Chapter 5 - Production: Lessons Taught

Introduction

We juggled multiple roles as we moved from pre-production to video production. In production, the making and doing of video storytelling, we found ourselves challenged in many directions, but this chapter focuses on one key aspect of our work together: teaching. In this section I highlight how youth participants identified, designed, and crafted video narratives that aimed to teach our audiences about the experiences of growing up with a heart transplant. In addition, I focus on how I sought to support and educate participants as they engaged in the craft of storytelling and video production. I begin this chapter describing the production process. I discuss the differing goals and responsibilities of each participant, and the types of media we gathered and created. Throughout this chapter, my intention is to highlight how our collaborative relationship was practiced, shaped and challenged in the process of constructing visual narratives.

During production, I was attuned to my roles as teacher and producer, while also tending to my fragile and developing collaborative working relationship with each participant. My focus was two-fold: 1) to teach participants how to co-produce their own visual shorts by developing storylines and storyboards that identified what visual sequences needed to be crafted and, 2) to produce and film visual sequences that supported our story lines, thereby attend to the craft of developing unique lesson plans. Both Michelle and Maria were novice filmmakers. During production, they were responsible for learning media production while developing narrative lesson arcs important to them. This chapter examines the teaching trajectories central to the narratives constructed during production. If my initial research question asked what stories young people wished to share, this chapter identifies and discusses

the lessons young people choose to shape for their audiences. In addition, by examining how our collaboration worked, this chapter also traces the unexpected ways in which teaching and learning unfolded during production.

Production

Production involves all aspects of gathering and creating the visual and audio materials used to craft our short narrative films. The materials we used included archival as well as original video and audio recordings. Our archival images were family photographs and artifacts that conveyed a sense of each participant's childhood experiences. The photographs focused on typical family events like vacations, first days of a school, and other celebratory occasions. In addition, archival images also included images of medical events that documented each participant's unique health journey. These images included clinic visits, hospitalizations and recovery as well as photographs with well-loved hospital caregivers like a favorite nurse or doctor.

The original materials we created for each film can be classified as either individually or jointly (team) produced material. All team-produced footage was filmed in High-Definition (HD) format using a Sony digital SLR and a point-of-view Gopro camera. In addition we used a Zoom H-1 Hand Recorder and RØDE smartLAV for independent audio. Participants also filmed sequences using a Canon digital SLR, as well as smart phones and ipads. The films we made together were the first time either participant had attempted to create their own visual narrative. During production, Maria and Michelle were each tasked with filming aspects of their stories on their own for one week. They were asked to film anything in their daily life they deemed significant and useful to illustrate the stories they wished to share. This task allowed participants to shape and design the visual motifs in their narratives by highlighting the key story trajectories that the films would center on. In other words, the sequences participants

identified and filmed were not addendums to our collaborative work. Instead they formed the key visual elements that guided our team production and each film incorporates significant portions of the footage they shot. With regard to research design, the task of filming story ideas on their own also afforded me teachable moments—opportunities to discuss and learn about the conventions of visual filmmaking. It also provided a research opportunity to learn what visual elements participants saw as important lessons to share with their audiences. Figure 5.1 shows the type of sources gathered and created during production.

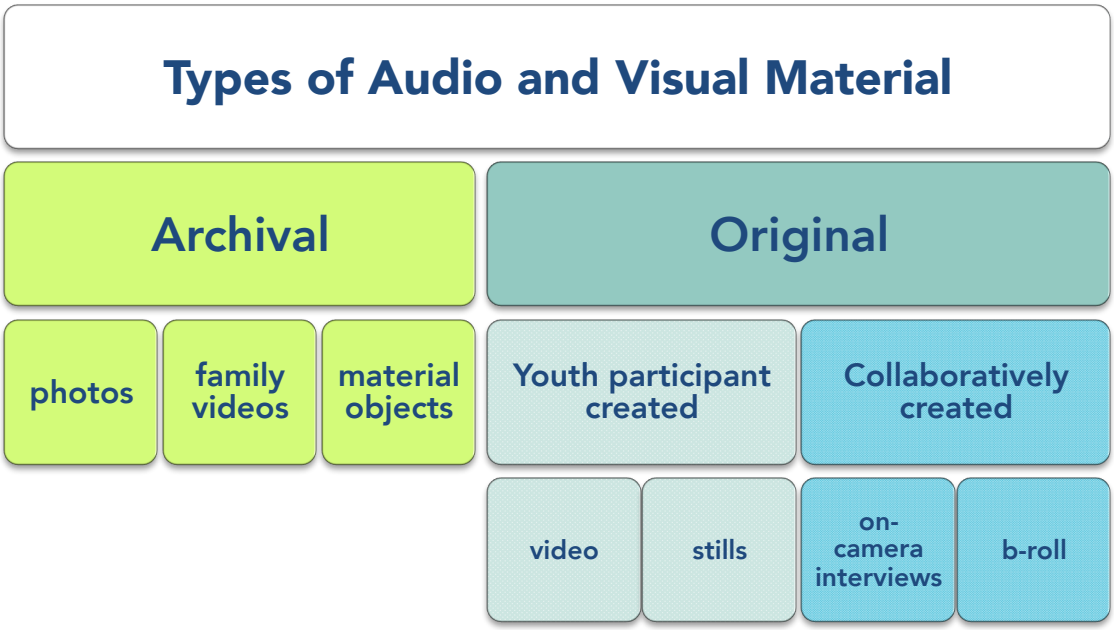

Figure 5.1 A hierarchical map of audiovisual materials used in our films.

Critical media production and youth-participant created media

Michelle, who early in our collaboration had spoken of her desire to create her own online YouTube programming, was an eager student of media production. She was keen to

learn about camera orientation, image stability, and scene coverage—all basic camera skills. Michelle created a variety of sequences over the course of production. Together, we reviewed her footage and discussed which sequences to incorporate into the final film as well as strategies for re-shooting sequences in order to better support her narrative. These discussions focused on the quality of the images, often involving inadequate lighting or background noise that interfered with the visual information she wanted to focus attention on.

For Maria the process of teaching and learning critical media production was slightly more mediated. During our face-to-face meetings we discussed and demonstrated camera framing and conventional ways for introducing and filming visual sequences. Though I shared conventional approaches and provided examples of how they could film their sequences, participants were free to experiment and develop their own style. They were encouraged to film and choose what they wished to share with me. Maria and I reviewed and discussed her footage primarily during video conferencing sessions. This mediated distance added a technical challenge that prevented an easy back and forth between us and between the visual materials we were viewing, thus hindering attempts at delving into the finer-grained analysis that Michelle and I were able to undertake.

Storyboards

Our production meetings led us to create storyboards of our work-in-progress. Storyboards are graphic organizers that let production teams map a film's story arc. Sophisticated storyboards can take the form of animated shot lists thereby saving production costs. Our storyboards were simplified graphic organizers that, based on my suggestion, we divided into a three-act structure. Generally Act One focused on introductions and included participant's family and medical backgrounds. Act Two focused on specific lessons participants hoped to impart. Act Three focused on summary conclusions. The three-act structure served

more as a guiding template than a rigid template and it allowed us to develop our story ideas, organize accumulating footage while also revealing areas where our story and visual storytelling needed further work. Figure 5.2 is an example of one of the storyboards Michelle and I created collaboratively. Initially, we storyboarded using index cards and large post-it notes that we would arrange and re-arranged during production meetings. At one point we used a free online program that allowed shared access, thereby adding another layer for documenting our storytelling process. Unfortunately both participants found the program too unwieldy to proceed and, after limited use, we returned to our lo-fi index cards during our production meetings.

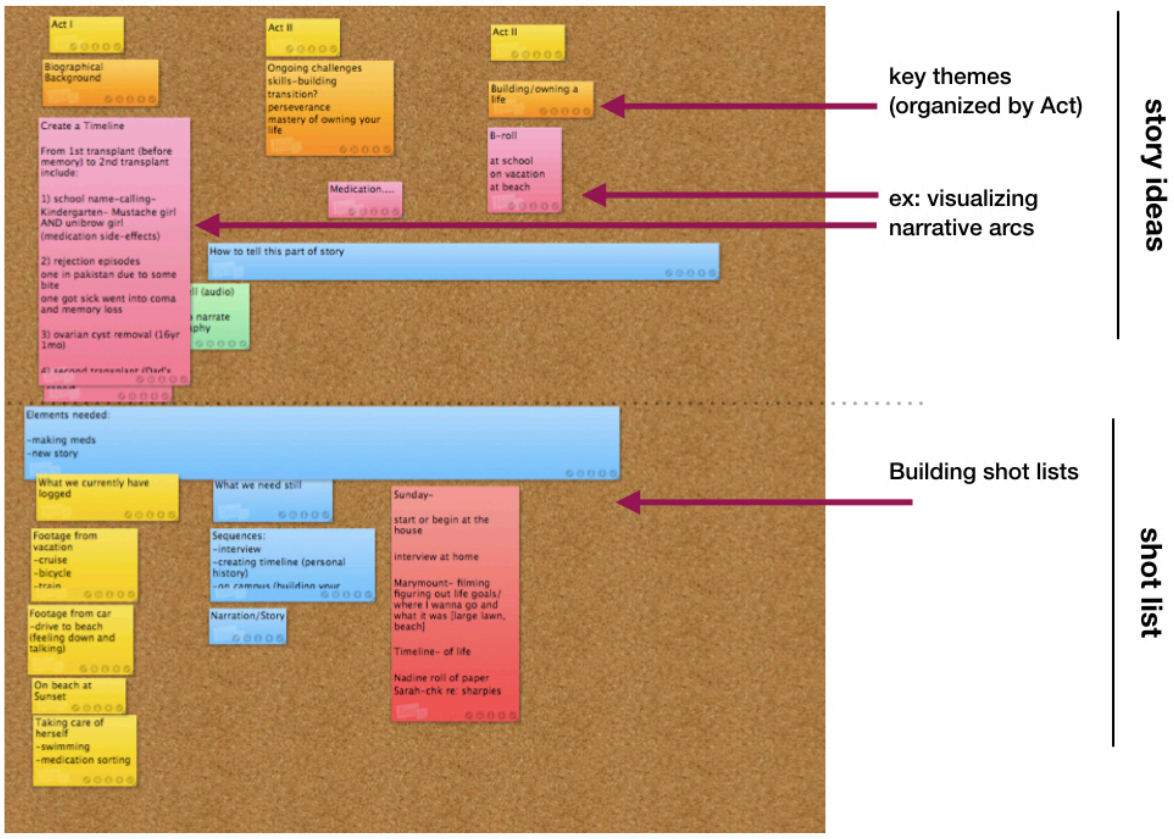

Figure 5.2 Annotated Storyboard

Collaboratively created media

Because participants were new to filmmaking, the days of team production were designed as focal points, a critical opportunity for joint production devised to provide the connective tissue for each short film. During team production days, we conducted on-camera interviews organized around the story ideas developed during pre-production. Unlike research interviews, our on-camera interviews were conducted with special attention to storytelling. These were performative interviews. During pre-production we had discussed and agreed on the story ideas we would cover. Once in production, my focus in conducting interviews was to elicit these stories and attend to whether a full narrative arc was conveyed for each storyline. During our interviews, I would check-in with participants to make sure that they were satisfied in their telling. Often multiple takes were filmed. These re-takes were initiated by each of us during the interview, and usually focused on correcting a turn of phrase or ensuring a full sentence was uttered. The speed of speech was usually a factor and my oft repeated request for a re-take typically involved asking participants to repeat the story exactly as before only much, much slower.

At times, the interviews touched upon deeply held emotions. In these instances, I made certain that participants knew they held the authority to continue or stop the interview at any time. On one occasion I stopped the interview when a story had become particularly painful. We stopped filming, took time to compose and gather our thoughts, spoke about where we wanted the story to go, and then restarted. I note this now, because our practice runs counter to most documentary television production I have participated in where heightened emotions are often elicited for narrative effect. In our collaborative practice, our research ethics involved the explicit understanding that neither Maria nor Michelle's emotions would be exploited for the sake of a film.

Both participants proved to be talented on-camera storytellers. In particular, Maria had a preternatural talent for projecting ease and confidence in front of the camera with grace and good humor. Initially, I did not register this as her particular skill, strange, since I am acutely self-conscious and uncomfortable in front of a camera. Nevertheless, because our recording equipment required us to break every twenty minutes to allow the camera's motor to cool down, I quickly came to realize that the minute we stopped recording, Maria would request I unplug and remove her lavalier microphone and proceeded to turn off the auxiliary camera that was recording our research footage. In these moments, Maria was visibly relieved to not be a focal point of a technological camera gaze even as we continued discussing and planning further aspects of our production day.

In addition to interviews, on days of team production we filmed b-roll—visual sequences designed to illustrate parts of a story as well as provide coverage that allowed us to transition in and out of interview topics and shots. These sequences were not narrated though ambient audio was recorded. B-roll sequences included Michelle and Maria performing various physical activities such as walking through the camera frame, skateboarding, swimming and ultimately riding rollercoasters. The activities we filmed were collaboratively chosen to reflect aspects of each participant's lives that were meaningful to them and their life stories.

Teaching lessons

The videos we made were intended and designed to be educational, lessons in critical media literacy production[193] for participants that resulted in the creation of educational media for a wide-ranging audience. In recruiting participants, I asked each of them to consider what

[193] Kellner and Share, "Toward Critical Media Literacy: Core Concepts, Debates, Organizations, and Policy"; Hammer, "Critical Media Literacy as Engaged Pedagogy."

life lessons they wanted others to learn. Built into the research design was the recognition that youth participants were also knowledgeable actors. The stories Maria and Michelle identified as important to share ranged from procedural, how-to, lessons, to more conceptual ones including life-skills lessons for living with a heart transplant.

Michelle's lesson in "How To Make My Meds"

As discussed in the previous chapter, determining an intended audience was a key aspect of our pre-production work. This decision helped provide a context for storytelling. For example, once Michelle determined that one of her target audiences was, primarily, other transplant recipients, a lesson plan emerged. Michelle wanted to teach others how she "made" her medicine. When Michelle first mentioned the idea of "making her meds" to me, I took this to mean that Michelle needed to craft her medication in some way prior to taking them. I imagined something akin to Michelle needing to mix two or more medications together in order to heighten their effectiveness. I was wrong. When Michelle said she "made" her meds, she meant that she sorted, organized and verified her medicine. She checked their expiration dates, evaluated if she needed to restock by ordering additional medication, and made sure that the quantity she had sorted into the large weekly medication containers she owned was correct. For Michelle, this was solitary work that required concentration and took time. Once Michelle determined that she wanted to teach others about this process, Michelle began filming herself making her medications. She filmed multiple sequences of herself organizing and sorting her medication. Each step in Michelle's "how to" segment needed to be discerned, described and filmed so that her audience could follow her sequence as a logical progression. Michelle hoped that, by seeing how she made her meds, her audience would leave knowing that they too could devise a procedure that worked for them. To our surprise, as we tentatively began screening

the video for undergraduates, their reaction to simply seeing the quantity of medication Michelle needed to manage each day and each week was a revelation to many. Their reaction gave Michelle and I a sense of the nested lessons embedded in our short video. For each overt lesson: this is how I make my meds, a more generalized lesson on the daily self-care responsibilities that all transplant recipients practice could also be gleaned.

Scales of Inquiry

A different set of dynamics shaped my work with Maria and the remainder of this chapter primarily focuses on my work with her. For one, when Maria and I met face-to-face we were usually joined by Maria's mother. This was a logistical issue as much as a convenience issue. Maria did not drive, and when we met to discuss our work, we usually met in public spaces. As a result, Maria's mother accompanied Maria, often sitting nearby but, when space was limited, sitting with us and joining our talks. As our collaboration grew, Maria and I would have virtual meetings alone and, on our day of team production, we worked together outside of the presence of her parents. Still the presence of a third-party in our collaboration impacted our work together. Certainly, Maria's parents facilitated our working relationship. Her parents shared their family's story and encouraged their daughter to share hers. They also provided transportation, family time and encouragement for our project. In addition, however, they also impacted our dynamics. When Maria and I were alone, Maria could be a student, researcher, and teenager. When we worked in the presence of her parents, she inhabited all these roles, but she was also, always, a daughter. Maria's parents also impacted my sense of self in their presence. For although I was always attuned to my primary responsibility to Maria, when parental interactions with their daughter occurred—often teasing, discipline, or guidance—I became keenly aware of my role and the transitory nature of my presence in their lives. This is

to say that this study is not an analysis of family interactions. As a researcher, I understood Maria's chronic heart condition as an ongoing source of family trauma, economic stress, and concern. As a parent, I also understood the simple everyday challenges of navigating family life. I have strived to delimit my discussion of these interactions to their impact on our storytelling project. I remain profoundly grateful to Maria's parents for allowing Maria and I to work together. Still, the presence of Maria's mother impacted Maria's stories in specific ways, which I detail below, but also in a broader sense, one that is more difficult to define. In every story discussion that took place between Maria and I, Maria references her mother as someone she looks up to, loves, is frustrated by, wants independence from. As a daughter and mother myself, I recognized and had sympathy for these feelings. These are the emotions that imbued our work together.

There is another sense in which the dynamic between Maria and I was different than the dynamic between Michelle and I, and this pertains to story. In our first pre-production meeting, Maria offered three story ideas. She first suggested centering our film on medication and how it organizes her day. In addition, Maria also suggested telling the story of her thoracic scar—a long surgical scar that runs vertically down the center of her chest from breastbone to navel—in ways that her peers might understand. Lastly, Maria wanted to convey to teachers and classmates a sense of her life, interlaced with medical concerns, but still as a person, an individual navigating her transition from adolescence to adulthood. Each of Maria's suggested storylines were consistently directed to an audience of peers and adults with whom she engaged with on a daily basis. What differed across these story arcs was a sense of scale. Maria knew who her intended audience was from the start and she wanted them to gain a sense of her life as a heart transplant recipient. Yet what Maria wanted to convey varied from the specific: how to tell the story of her scar, to a both more general and deeper perspective of life

as a heart transplant recipient. What Maria wanted others to understand is how medication impacted the rituals of daily life. Moreover, Maria wanted to convey what meant to be known as "the heart transplant student," as opposed to being recognized simply and foremost as Maria. She wanted to educate her community about her health in ways that provided a deeper understanding of her chronic condition while mitigating an alarmist reaction in order to be understood simply as Maria, a teenager, like others, navigating her path to adulthood.

The remainder of this chapter examines how Maria and I produced visual stories from these three nascent story ideas. By examining the making and doing of video production, I show how teaching lessons became learning opportunities for Maria and I.

Lesson one: Finding the right words

The story of Maria's scar presented me with a teaching challenge. Maria told me that she is often asked about the long surgical scar that is visible if she wears a V-neck t-shirt. Maria shared a typical exchange with me:

> A lot of people are like "What's the scar from?"
>
> And I'm like, "Oh, I've had two heart transplants."
>
> And they're always like, "Oh, what happened?"
>
> I don't know how to explain it.
>
> I don't know the right words to explain it without getting it wrong, or
>
> sounding like it's superbad.

When Maria tells me that she does not know the 'right' words, my reaction is immediate. Maria presents me with a lesson plan and teaching opportunity. During our on-camera interview we will engage in a lesson on "how to tell a story." I plan a strategy. I tell her that during our

interview I will ask her to tell the story of her scar, and that she is free to tell it anyway she wants, as often as she wants, until she is satisfied in the telling.

What makes this an ideal lesson plan is that, because we film multiple takes, we can edit the story, weave portions of one take into another, be very deliberative, very intentional in this narrative arc. Furthermore, once our film is complete, I envision Maria being able to show this sequence to anyone who asks about her scar, relieving her from an obligation to retell the story because it has been recorded, but also providing her with a storytelling template. A version she has crafted and honed, and can edit or re-tell in any direction that makes sense to her.

On the day of team production, after we have set-up our equipment and begun filming, the story of Maria's scar is one of the first questions I ask. Beforehand, off-camera, Maria and I consult. I tell her the subject and try to provide a similar context for answering that she has previously shared with me. The equipment is then turned back on and filming begins:

Me: I'm a new kid at your school. I see your scar and I'm like, "Hey what's going on? You said your chest has been opened twice. What's that mean?"

Maria: So, my chest has been opened twice. So that means they have opened up my chest, my bone, my muscle and they have taken out the heart that was super bad and they had put it for testing and they had taken a new heart—mine was from a kid who had died from a car accident—and they had put it back in mine. So it's kinda like I had died once for a little bit, and they had brought me back to life.

At the time, I remember listening closely as Maria responding to my question. We had planned a strategy. I would ask a question that she is often asked, and Maria would respond in a way that she was comfortable. We would repeat the process until Maria felt she got the wording

right. On this first take, as her story unfolds, Maria's tale moves in a surprising direction. She says, "It's kinda like I had died once...and they brought me back to life." I remember tentatively halting in the moment before deciding to follow her narrative path. I ask, "Do you think about this?" and Maria responds:

> I do. When I imagine it, I think where was I? What was I thinking then? Was I thinking... did I see like white or black? What did I see? You know, 'cause I don't remember. I remember going under anesthesia and then just nothing else, and then waking up in a room and my parents and my grandparents and brothers and everybody there. What did I see? What did I think about when I was there?[194]

During the interview, and even now as I am writing, I remember having two reactions. The first was concern that we would not accomplish my teaching goal, a lesson in how to tell a story. The second was a sense of awe. What moved me then, and still with hindsight, is not simply that she was able to speak openly about such a profound experience. What I found extraordinary was Maria's intellectual honesty, her willingness to revisit that time, to wonder about the moment in-between. Maria's story touches upon multiple transitions—the transition to a new heart, the transitory state between life and death, between memory and forgetfulness, and ultimately between an experience of utter existential aloneness and emerging from that experience surrounded by the company of her family. Through all these layers of reflection, Maria retains the courage to ask, "What did I think when I was there?"

After we filmed this sequence, I asked Maria if she wanted another take, another chance to tell a different version of this story, but she declined. I remember being humbled. Not because my ideal lesson plan lay abandoned, but because Maria taught me something about the impact of storytelling itself. Critical disability scholars highlight the entangled possibilities

[194] Modified transcript

inherent in methods that center listening in research.[195] Here, in this moment of listening an entangled possibility emerged. I learned that it was impossible for Maria to answer my prompt, "Tell me about your scar?" with a canned, rehearsed story. Instead, in the moment Maria manages to find the "right" words to tell a story about her scar. It is a storyline that diverged into another path, one that encompasses her memories of the surgery that created it and the ways in which her encounter with death, linger and infuse her life with a sense of wonder. In the end, a lesson plan in how to tell a story becomes a lesson in the possibility of collaborative storytelling, with its relational commitment to openness and flexibility that can lead to unexpected pathways that transform the story of her scar into a story of Maria.

Lesson Two: Compliance, reliance and interdependence

For Michelle, the practice of "making her meds" was a lesson in the planning and organizing of self-care on a scale of time defined by days and weeks. When Maria said she was interested in telling stories about medication, her focus was on the time-scale of hours and months. As we were brainstorming lessons to share, Maria tentatively offered a story idea centered on medication:

Maria: I was thinking about maybe medication would be the most important thing to focus on....

Me: So what part of that?

Maria: Like what's expected. Like it's important to set an alarm and pick a time. For example, I have eight o'clock in the morning and eight o'clock at night. And I have alarm set so I would remember. And then...

[195] De Schauwer, Van De Putte, and Davies, "Collective Biography."

Mom: And to do it the same time how important it is to do with the same time every day goes along with that

Maria: Yeah. And then, how did I write this?

Maria: Like how many pills or how many medications that you would have to take for it.

Long after we finished our film and had begun initial screenings, I transcribed this exchange and shared it as part of a co-generative research discussion in Federica Raia's LaB. It was in this environment that one of the participants, Dr. Ana Torres, began developing, what she called, a 'vocabulary inventory,' from Maria's talk (see Table 5.1).

Table 5.1 Maria's vocabulary inventory

medication	in the morning	same time
important thing	eight o'clock	how important it is
set an alarm	at night	same time
pick a time	alarm set	every day
eight o'clock	remember	

Torres suggested that Maria's vocabulary highlights how temporality was imbricated in an ethical discourse on medication management. Maria's language reveals how memory and duty function in the twice-daily ritual of taking her medication. Other participants of the LaB noted how Maria's mother interjected in this discussion— "And to do it the same time how important it is..."—with a parental lesson of her own that underscores the importance of timing to Maria. These rich analytic contributions to the transcript texture and layer my own understanding and memory of our interaction. However, during the creative process of producing the video, the

specificities in these analyses, remained opaque to me. Instead, my main concerns at that time were about safe-guarding our collaborative relationship while navigating the multiple, power-laden relationships at play. For one, I was keenly aware of the child and parent interactions in this exchange. I strived to remain impartial, neither affirming nor dismissing the importance of consistency in timing medication. In that moment I was an observer and tried not to engage in their dynamic.

This familial dynamic also occurred later in our conversation and again required careful negotiation. As we continued to brainstorm story ideas revolving around medication management, Maria's mother began telling a story that had occurred the previous summer. Though her mother began the story, Maria added details, shaping and elaborating key events. In effect, mother and daughter began co-telling a story of missed medication that had led to a family crisis with key narrative shifts in points of view. For Maria's mother, the story was told from the position of a mother discovering multiple doses of medication her daughter should already have taken. For Maria, the story was an explanation of the reasoning behind the multiple missed doses. What happened was not contested. Instead Maria wanted to convey to me how missing one dose had led to an escalating problem. Maria told me that when she realized she had missed a dose, she knew there was a problem but did not know how to correct it. She worried that if she took the medication, in effect double dosing to make up for the missed dose, she might overdose. She was also ashamed, knowing she had made a mistake but wanting neither to disappoint parents or doctors who regularly monitor her health, nor be admonished for missing her dose. When she missed a second dose, the uncertainty and hiding only grew leading, over time, to a cycle that repeated. In the end, Maria's mom discovered 38 missed doses hidden in Maria's room.

As a teacher and film producer, my mission was to support and recognize Maria's efforts in defining story ideas for our video. I pondered how to translate Maria's concern for medication management into a visual sequence that could support our story, with an added understanding that both Maria and her mother identified medication management as a critical responsibility that textured Maria's daily thoughts and actions. I felt that telling the story of multiple missed doses could be a powerful teaching tool for others. However, because the discussion of this story had been initiated and heavily shaped by the presence and contribution of Maria's mother, I was unsure how Maria felt about sharing this story on camera. I knew that Maria's mother thought it was a critical lesson to teach other families, but I was also certain, and Maria's mother had explicitly agreed to this, that Maria had the final say over which stories to tell.

On our day of team production, as we planned and discussed my interview questions, I asked Maria if this was a story she wanted to share. It was a complicated narrative, multifaceted in detail, occurring over months, in multiple locations and with different family members. As hesitant as I was about embarking in this direction, it was surprising how readily Maria decided to share that story as part of her film. On the day of joint production and multiple times thereafter, I gave Maria the opportunity to omit this tale. Yet again, Maria taught me the value of her storytelling. In order to transform her story into a learning opportunity, Maria and I decide to tell the story and highlight the solutions Maria and her family came up with to ensure a mistake of this magnitude would not be repeated. By focusing on problem-solving, Maria's story becomes an exemplar, a way to discuss medication management while also demonstrating for other young transplant recipients how they might resolve their own problems. Later, in screening Maria's film for doctors, Maria's story of missing medication is the one story element that they overtly respond to. In multiple instances pediatric and adult cardiologists who specialized in heart transplantation noted Maria's story as concerning, important, and valuable

to share with other transplant recipients. In one instance, a cardiologist asked if he could show Maria's film to a patient currently hospitalized, whom he suspected had missed medication but was unwilling to discuss it.

During production this storyline raised several concerns that required additional production. First, we needed to find a way to visualize and illustrate Maria's story in ways that would allow us to edit in and out of the multiple takes without detracting our audience. For example, when Michelle presented her "how to" sequence, we had footage that both Michelle and I had filmed of her making her meds. When Maria talks about missing a series of doses we lacked a visual element to support her on-camera interview. My solution, this was an instance where the collaborative labor fell principally to me, was to create rudimentary cartoon-like graphics that included alarm clocks and wrist watches, and individual pills using Adobe Illustrator, a program that was new to me. Though the visual elements are limited by my skill-level, the graphics allowed us visual coverage to illustrate and support Maria's story.

A more critical concern came after we began screening a near-final cut of our film. When I screened the film for Federica Raia, she was concerned that Maria's story was providing an unintended lesson. Dr. Raia worried that other young transplant recipients would hear that Maria had missed 38 doses, seemingly without consequences, and believe that they, too, could miss medication without it impacting their health. This was a potentially life-threatening lesson. I knew our story needed to be clarified. Maria and I met face-to-face to discuss and work on our film. Because of our physical distance, face-to-face meetings were also high-stakes meetings. This was an opportunity to fix a critical problem. I was also concerned about a technical issue. I knew that the quality of production audio would be difficult to match to our on-camera interview audio in the best of circumstances and nearly impossible without identical recording equipment. This is how Maria, Maria's mother and I found ourselves crowded

together into my car in a public parking lot, trying to record an audio-only sequence that we could edit into Maria's narrative.

What follows is an extended transcript of our interaction. In the transcript you can sense the high-stakes nature of the meeting for Maria and myself. It is an atypical example of our work together. It is also an instance when I move the scale of analysis closer by providing a transcript that traces the minute interactions that occurred during our recording session. This encounter occurred within the larger context of producing this specific storyline. It offers an example of the nested interactions that took places during our collaborative research. It is also an example of a teaching lesson, one that is essential to this ethnography of learning.

Lesson Three: Making mistakes and the welter of collaborative work

Prior to our transcribed encounter, Maria, her mother and I watched and discussed an assembled cut of our film. At this stage of the editing process, our video assemblage was still missing a crucial scene that we planned to film in the near future. The focus of this production meeting was specifically on Maria's medication management story in the context of Dr. Raia's comments. Our goal was to record an audio insert for the narrative that would tell audiences what actual and potential repercussions Maria faced in missing medication. Even though we were meeting in a public space, I still had not planned on recording the session in my car. However, when it became apparent that the ambient noise-level was simply too loud to record a clean audio, we moved our meeting to my car in the hopes that it would provide a sound barrier and help us complete our task. Why is the location important? It is important because it was a mobile setting in which we could dampen some of the exterior noise by moving away from noisy areas. It also matters because a car is a small, cramped space. For the recording,

Maria's mother sat in the front passenger seat. Maria and I sat facing each other in the back seats (see Figure 5.3).

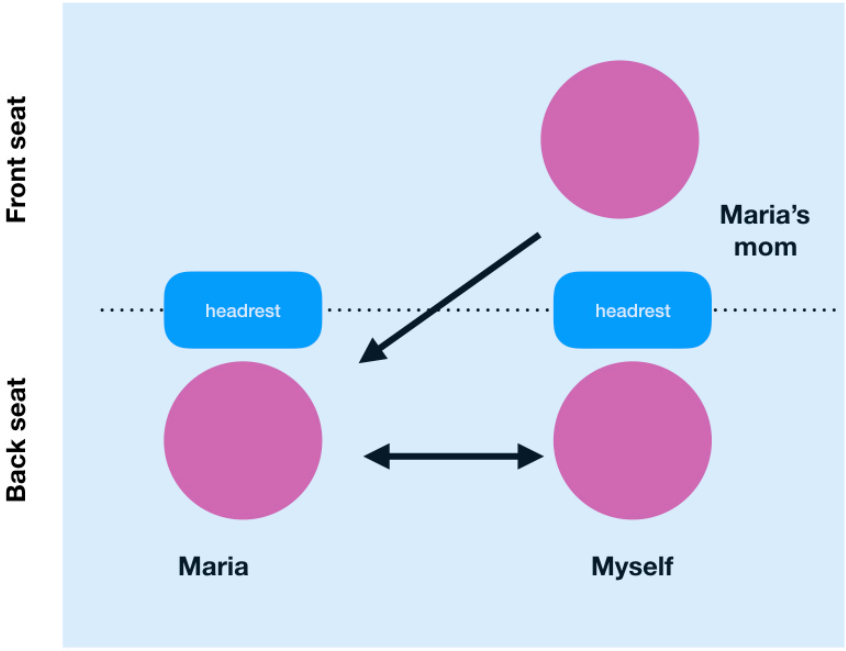

Figure 5.3 Diagram of our seating arrangement

In this setting there was no space for privacy. No chance for any of us to compose ourselves alone before we started working. As we sit, Maria's mother orients herself to face us. A headrest creates a visual obstruction between her and I, but not between Maria and her mother. This seating dynamic underscores Maria as the focal point of this interaction. She is expected to perform, to find the right words, in front of two women with whom she has relationships of differing power dynamics. Under these, less than ideal conditions, I turn on the recorder and we begin.[196]

[196] For this extended example I follow the transcription conventions for spoken discourse developed by Jefferson, described by Sacks, Schegloff, and Jefferson, "A Simplest Systematics for the Organization of Turn-Taking for Conversation." Participants in Raia's LaB were generous in helping fine-tune this transcript. In particular, I wish to thank Candy Goodwin for her notes and corrections. All errors are my own.

1.	Maria	p(h) ((sounds like bubble popping))
2.	Maria's Mom	° stop~it.
3.	Nadine	ok// so um,
4.	Maria	//°hi guys welcome to my ( ) heart
5.		(2.96)
6.	Me	so basically
7.	Maria	((exhale)) °hhh
8.	Me	what i want you- ((repair))
9.		SO the idea is (1.04)
10.		you missed thirty eight doses,
11.		and what were the consequences of missing that.
12.		(1.7)
13.	Maria	um, (.71) i~had~to~go~to~a~lot of doctors appointments
14.		um, i missed um a science lab that
15.		i~really~wanted~to~do,
16.		um i had to do a lot of blood tests, i
17.		I had~to~go~to~the~doctor every week to make sure
18.		that i wasnt rejecting,
19.	Me	uh one~more~time um (.67)
20.		so remember that when you//
21.	Maria	//((drinking thru straw sounds))
22.	Me	answer the question you kinda have to add
23.		you kinda have to say what the question was like
24.	Maria	oh thats right °whoops
25.	Me	((performative)) Even though i missed 38 doses uh
26.	Maria's Mom	((whispering)) °sit still
27.	Me	or i ma ((repair)) i missed 38 doses
28.		and luckily i didnt go into rejection but
29.		you know//
30.	Maria	//mmhmm
31.	Me	but this is what happened
32.	Maria	okay (1.03) uhaah::::
33.		((stretches utterance to 1.42)

34.		i forgot im sorry
35.	Me	um its~okay
36.		ah eve- ah i missed 38 doses right
37.	Maria	uh hu ((giggling))
38.	Me	even though i missed so many doses
39.		i luckily i didnt go into rejection
40.	Maria	okay
41.		(.86)
42.		even though i missed 38 doses um i
43.		luckily~didnt~go~into~rejection
44.		~but~I~had~to~go~to~a~lot~of
45.		~doctors~appointments every week
46.		um i missed uh a science lab
47.		that~i~really~wanted~to~do
48.		i had to a lot of
49.		um blood tests to make sure that i wasnt rejecting,
50.		((sounds of ice/drink swirling))
51.	Me	((whispering)) °and increase your medication
52.		so ok so im gonna//
53.	Maria	//oh thats right
54.	Me	ask you to do it one more time
55.	Maria	ok
56.	Me	a little slow::er
57.	Maria	ok ((smiley voice))
58.	Maria's Mom	((whispering)) °stop now
59.	Maria	I cant
60.	Maria's Mom	you shouldnt had your coffee
61.	Me	ehh huhhh
		____
72.	Maria	im sorry (.) okay
73.		w(h):::ew ((exhale)) hhh
74.		(.72)
75.		even though I missed 38 doses,
76.		i luckily wasnt rejecting,
77.		uh uh they uh they raised my medication
78.		i had to go to the doctors every week,

79.		and i (.) had to get my blood tests as well to make
80.		sure that
81.		i wasnt rejecting.
82.		(1.32)
83.	Me	((directing)) *hh so I was very fortunate
84.	Maria	((inhale)) *hh
85.		(1.52)
86.	Me	add that
87.		(.48)
88.	Maria	uh so I was very fortunate
89.	Me	perfect eh no you wouldnt say that
90.		say that I was lucky
91.	Maria	° oh::: ((.82 "oh"))
92.	Me	no?//
93.	Maria's Mom	//i was very lucky that//
94.	Maria	no i was ((:37))
95.		that ° was ° good
96.	Me	yeah//
97.	Maria's Mom	//missing those doses didnt
98.		cause prob- any problems that it could have
99.		or something
100.	Me	any more complications
101.		i dun uh yea
102.	Maria's Mom	hh ((throat clearing))
103.	Me	its in your voice//
104.	Maria	//okay
105.	Me	so you have to say it (.) um
106.		°h but basically the idea is (1.33)
107.		an 11 year old//
108.	Maria	//mhmm//
109.	Me	//who you started talking to
110.		is gonna see that and go
111.		oh:: 38 i ca- thats- as long as i do 27 ((singsong))
112.		im not- its gonna be fine
113.		so were trying to avoid °hh the
114.		idea that someone else can d-do//

115.	Maria	//yeah ((ice tinkling))//
116.	Me	//that right
117.	Maria	mmhmm//
118.	Me	//so thats like what would what would yo-
119.		what advice would you give to someone like why it isnt
120.		okay to miss
121.		why it isnt okay to miss 38 doses.
122.	Maria	um it isnt okay to make (1.7)
123.		uh it ***isnt*** okay to miss 38 doses because
124.		um unlike me I-was-very-fortunate
125.		to not (.) reject? (.66)
126.		***but*** you know you::
127.		could-reject
128.		you:: could be (.) listed again.=
129.		you could have to have another heart.=
130.		you could do~all~these~other~things
131.		that i fortunately didnt do.
132.		mhm
133.		(1.35)
134.	Me	i think thats-
135.		i think thats perfect//
136.	Maria's Mom	//yeah thats good-//
137.	Me	i think thats exactly the tone you wanna get
138.	Maria's Mom	yup
139.	Me	because otherwise it was us telling you what to
140.		say and this way
141.	Maria	yeah
142.	Maria's Mom	yup no thats good
143.		good job

I share this long transcript, unusual in Conversation Analysis, because I want to trace the how this encounter unfolded over time in the activity of recording a pick-up for our collaborative film. Maria reveals an ambivalence at the very start of the recording whispering into the microphone, "Hi guys, welcome to my (?) heart", (Figure 5.4, line 4, note, despite multiple

attempts to transcribe this portion of audio, it remained indecipherable). At the time, I understood Maria's gesture simply as her testing the audio connection, an activity that I was engaged in as I was also trying to insure that our recording equipment was functioning properly. In retrospect, however, I read this as a sign of Maria's anticipatory wariness, tempered with age-appropriate sarcasm.

Although we each know the context for this recording, here in my producing role I begin the session by guiding Maria toward a response that will solve a narrative problem. I start by asking her what the consequences were of missing so many doses (lines 8-11). In Take 1 (Figure 5.4), we see Maria responding to my prompt by seemingly offering a series of bullet points (lines 13-18):

- I had more doctor's appointments
- I missed a class I wanted to participate in
- I had more blood tests, (i.e. more needle pricks)
- I had to go to the doctor every week to make sure I wasn't rejecting.

At this point, I interrupt Maria, reminding her that for the purpose of this recording she needs to try to answer in full sentences while also incorporating my initial prompt into her answer in order to provide a context for her audience. This is a difficult task for experienced interviewees. I provide Maria with some suggested openings, "Even though I missed 38 doses..." or "I missed 38 doses and luckily I didn't go into rejection..." (lines 25, 27-28). Maria's mom also provides direction, telling Maria to "sit still" (line 26).

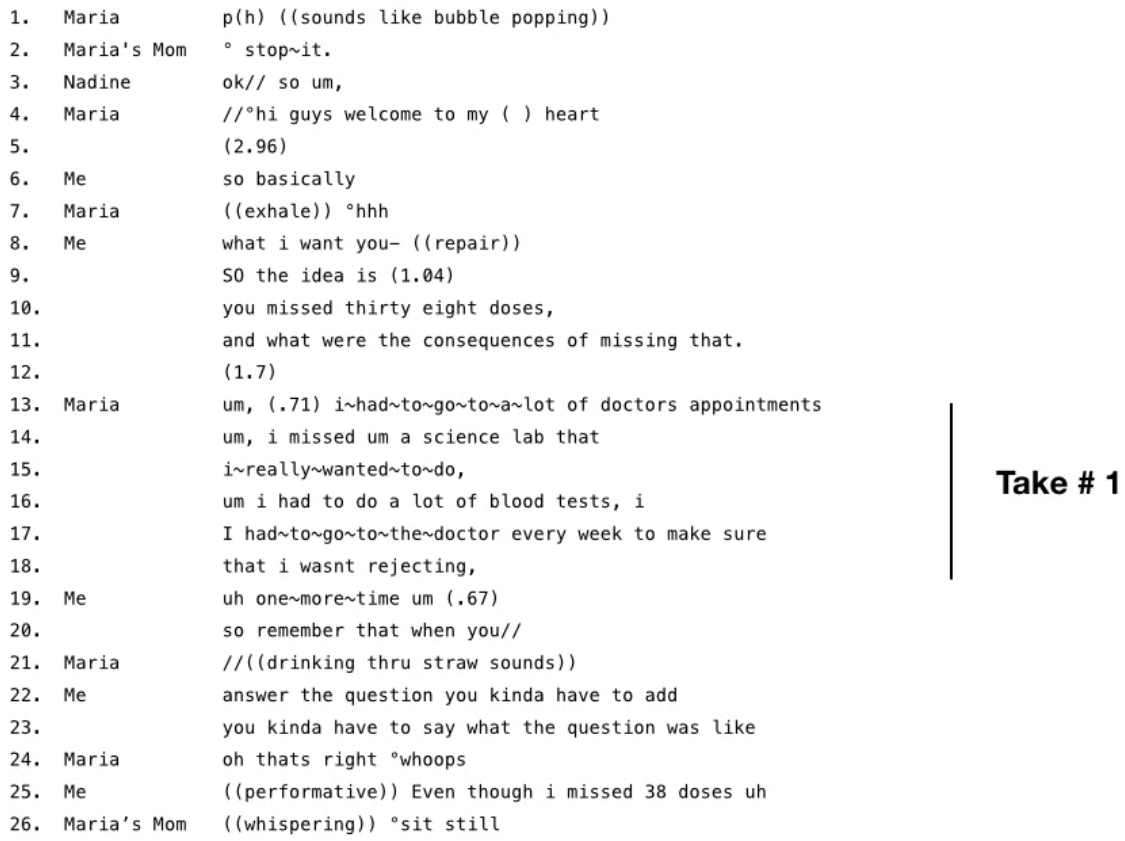

Figure 5.4 Failure and recovery in collaborative work

Maria is tasked with juggling these disparate directions and tentatively begins another take that quickly disintegrates before it has a chance to develop when Maria says, "I forgot, I'm sorry" (line 34). Here I try to help Maria with a reminder (line 36; line 39). Maria begins Take 2, running through her "lines," as if trying to finish a task as soon as possible (line 42-49). When she pauses, searching for the next response, I whisper one of her bullet points as a reminder to her (line 51). This initiates another break (lines 53-54). Again, I give Maria direction, "a little slower" (line 56), followed immediately by Maria's mother providing her own direction in response to her daughter's fidgeting. She tells her to "stop now" (line 58), followed by some teasing back and forth between mother and daughter (lines 59-60). Although I laugh, it is not in response to humor but discomfort (see Figure 5.5). [197]

[197] Wagner and Vöge, *Journal of Pragmatics: Special Issue on Laughter in Interaction in Honor of Gail Jefferson*.

Figure 5.5 Failure and recovery in collaborative work

Maria apologizes to us, takes a breath, and begins Take 3 (Figure 5.6, lines 72-75). This time we get through Maria's list of the repercussions she experienced but hit a stumbling block when it is time to address the potential health risks of missing medication. Again, I try to assist Maria by offering speech to help make that turn: "so I was very fortunate" (line 83). Maria is now in an unenviable position. We have recorded multiple takes. We are all aware of time (passing) and space (cramped). I have offered Maria a line, and have placed her in a position in which she feels the need to parrot-back the line to me (line 88). Realizing this, I stop (line 89). Maria and I begin working together to find a solution (line 90-92) and shortly thereafter Maria's mother joins this dynamic to offer suggested speech (lines 93). In this section of the transcript there are multiple speakers (mainly Maria's mother and I), overlapping talk, long pauses (mainly Maria's). Although well intentioned—we are all trying to find a solution—this is the moment when the recording session has devolved and is no longer functioning. It has become a free-for-all. We are not a collaborative team. No one is in control.

Listening back to this interaction is painful. I am embarrassed by my failure as a teacher, researcher and producer. In this interaction, instead of providing support and enabling Maria to tell her story, Maria is silenced, denied her own agency, her voice, her words. The only redeeming aspect in this interaction is that at some point, I stop us all and change direction. "Dun uh yea" (line 101) is my inelegant utterance that leads to a restatement of our purpose. I try to convey to Maria: this narrative has to be in your voice, here is the context. We want to clarify to your audience that though you faced consequences from skipping medication you were also incredibly lucky because you did not experience a rejection episode. We want to minimize the chance that other young transplant recipients might hear your story and think it is okay for them to skip some medications. We want to convey that when you skip your prescribed medication you are taking an enormous, life-threatening risk (lines 103-121).

We start again. Take Four is the culmination of this recording session (Figure 5.7). It is Maria responding to my statement of purpose in the words she found at that moment (line 122-131).

Figure 5.6 Failure and recovery in collaborative work

109.	Me	//who you started talking to
110.		is gonna see that and go
111.		oh:: 38 i ca- thats- as long as i do 27 ((singsong))
112.		im not- its gonna be fine
113.		so were trying to avoid °hh the
114.		idea that someone else can d-do//
115.	Maria	//yeah ((ice tinkling))//
116.	Me	//that right
117.	Maria	mmhmm//
118.	Me	//so thats like what would what would yo-
119.		what advice would you give to someone like why it isnt
120.		okay to miss
121.		why it isnt okay to miss 38 doses.
122.	Maria	um it isnt okay to make (1.7)
123.		uh it ***isnt*** okay to miss 38 doses because
124.		um unlike me I-was-very-fortunate
125.		to not (.) reject? (.66)
126.		***but*** you know you::
127.		could-reject
128.		you:: could be (.) listed again.=
129.		you could have to have another heart.=
130.		you could do~all~these~other~things
131.		that i fortunately didnt do.
132.		mhm
133.		(1.35)
134.	Me	i think thats-
135.		i think thats perfect//
136.	Maria's Mom	//yeah thats good-//
137.	Me	i think thats exactly the tone you wanna get
138.	Maria's Mom	yup
139.	Me	because otherwise it was us telling you what to
140.		say and this way
141.	Maria	yeah
142.	Maria's Mom	yup no thats good
143.		good job

Take # 4

Figure 5.7 Failure and recovery in collaborative work

For our film we were able to edit together the various sections of her response in a way that addresses the problem we set out to solve. Much later, in the co-generative LaB, I present Take 4 as an example of Maria finding the right words, her words, to solve this problem but not

everyone is convinced. Indeed, if you read the transcript closely it is evident that many of the actual words Maria uses are words proffered to her earlier. Maria is reusing them, recycling them in order to respond to my prompt. Nevertheless, I maintain that a qualitative shift took place in our interactions. Instead of Maria having to parrot-back phrases for the audio recording, in Take Four Maria is allowed to answer the question in her own way, recycling and reusing language to reason and make decisions for herself. Chuck Goodwin identified this as co-operative action,[198] not simply mutual help, but the opportunistic conjoining of diverse resources in concerted action to innovate the present by adapting resources inherited from the past.[199] In this final production take, Maria's voice is heard. At minimum, that is the best interpretation to a complex and disheartening interaction. I include this discussion because this is also a part of research ethics. I want to show where mistakes got made, and how they got resolved in situ, because this is also an aspect of collaborative research and youth participatory engagement. It is especially true when young participants' unequal power relations are reified by authority figures—like teachers. What this lesson taught me was the importance of confronting and recognizing my own power-laden practices regardless of my good intentions. What I learned was the necessity of re-constituting our storytelling and research purposes in order to repair and care for my collaborative relationship with Maria.

Lesson Four: What drives me mad

The last story Maria wanted to share, was not so much an overt, discrete lesson as much as a glimpse into the challenges of being a student with a chronic condition. In our first

[198] Goodwin, *Co-Operative Action*.

[199] Goodwin, 477; Erickson, "Charles Goodwin (1943–2018)."

pre-production meeting while talking about school-life, brainstorming story ideas and getting to know each other, Maria paused suddenly in our conversation and shifted direction saying;

> What drives me mad is that every teacher I've ever had.
>
> Ever.
>
> Like in the past eight years has always been super-concerned with me going on fieldtrips.

Listening, my ears perk up. I know, as a producer, that stories emanating from passion can be powerful. Maria's mom adds to the conversation by commenting, "Well, she makes everybody really nervous." Maria quickly reinforces this insight by repeating and emphasizing, "Everybody." She continues,

> Like even the students I don't even talk to are like, 'Are you sure you wanna go? I mean you have to take a lot of meds. Are you sure?'

Maria's frustration and annoyance at being policed by students she "doesn't even talk to" is understandable. I imagine that our film might provide an ideal vehicle to address Maria's frustration and provide her audience with a fuller picture of Maria's life as an adolescent.

In many ways this story also provides a different perspective of our collaborative exchange. In the story of her scar, Maria crafted a moving tale of wonder and curiosity. In her story of medication management, Maria and I each took responsibility for certain storytelling tasks, but interlaced co-telling was not how our storytelling collaboration functioned. However, in this final story arc, it was only through our work together that Maria and I were able to transform the story of "what drives her mad" into a story that touches upon the challenges and complexity of navigating normal student life while living with a chronic condition that marks you as different.

Maria provides examples of the challenges that impact her life as a student. In developing this as a narrative story, my instinct is to counter the narrow perceptions that seem to define Maria's experiences in school by giving our audience a sense of Maria's hopes, dreams, and responsibilities. By showing her life as a multifaceted young person, my hope is that the film might change the ways in which her community sees and interacts with Maria as a student and classmate.

The final lesson in our film shifts the narrative arc from "what drives me mad" into a story of what Maria loves. Remarkably, our story becomes a tale about the energy and exhilaration she finds in riding rollercoasters. On the day of team production our interview touches upon the challenges of being a student in school with a chronic health condition. We discuss how frequent clinic visits and occasional hospitalizations impact Maria's life as a student, as well as her interactions with teachers and school administrators. She tells of her frustration of being known in classrooms as someone with constraints, as a problem to be solved. All these issues come to the fore when Maria discusses school fieldtrips as occasions fraught with tense negotiation. She offers a recent example of an end-of-the-year grade-wide celebration that includes a visit to an area amusement park. On every school excursion, Maria describes a de facto assumption that if Maria chooses to participate, she must also provide her own chaperone to monitor her health and medications. This assumption has impacted Maria and her family in multiple ways, many times, impacting work decisions, relations with extended family, and participation in school activities. When Maria's teachers and classmates raise concerns about her presence on the trip to the amusement park, what they do not know is that: 1) Maria has actually discussed rollercoasters with her cardiologist and has received a verbal authorization and assurance that as long as she enjoys them there is no health risk and, 2) Maria, her siblings

and father love to ride rollercoasters and visit amusement parks as often as possible, which in summers can mean every week.

In our film, Maria and I try to shift the stakes of storytelling moving from the specificities of memories and medication, to capture another scale of life impacted by medication and the perception and policing of others. In this sequence we tell the story of Maria as an adolescent in transition. Maria is forthright. She acknowledges that she is not an independent adult—a position she aspires to. She recognizes that she still relies on others to help her with her medication management and openly wonders why her medication schedule cannot be accommodated on school trips. Maria does not want to be chaperoned by her mother, separated from classmates, simply because she has to take pills at a specific time. She yearns for independence and does not want to be seen as the fragile girl, one who cannot handle thrill-rides. On-camera, when I ask Maria to describe the experience of riding a rollercoaster, she says, "You're head is back. It's fun. But it's so thrilling and so fulfilling." In our film the risk, danger and exhilaration of rollercoasters become a metaphor for living.

After our on-camera interview Maria and I eagerly determine that this story needs visuals of her riding a rollercoaster. So, after our day of joint production and even after our unfortunate audio-recording session, Maria, her parents and I spend an afternoon in an amusement park together riding, filming and capturing Maria's thrill, her adrenaline, her joy in life.

Conclusion

This chapter has sought to convey how collaboration worked during the production phase of our film. By examining how story ideas were translated into visual and narrative lessons, I have tried to show how teaching decisions were multilayered and negotiated

incrementally throughout production in overt planned lessons that came to naught; in story lessons that led us to new unexpected realms; and in the hardscrabble mistakes and challenges of crafting visual narratives. These teaching stories were led, at various times, by each participant in this research, by young and old, experienced and inexperienced, as well as by the community of scholars in the LaB who's conversations contributed and shaped my understanding. The next chapter examines the work of post-production and reflects on the learning stories that Maria, Michelle and I gleaned in our collaborative work together.

Chapter 6 - Post-production: Lessons Learned

Introduction

Chapter six continues our ethnography as a movement through time by focusing on the changing nature of collaborative work in post-production. Post-production is the final phase of filmmaking when the materials you have gathered and created are edited into a film. Although editing is taught and organized professionally as a separate, discrete phase of filmmaking, often, and in the case of this research, there is a continuum between production and post-production. As you assemble and review storylines you begin to identify the strengths and weaknesses of your material. By stepping back and seeing the footage in its totality you detect narrative sequences that are missing or need further clarification. Post-production is when many of these issues come to the fore leading you back, at times, to production for "pick-ups" or new sequences entirely. This chapter details how our collaborative relationship evolved during post-production. Further, it shows how, as our stories became realized and defined, each of us were able to reflect back on our work together and begin identifying the lessons we learned.

Division of Labor

Of all of the stages in filmmaking, post-production is one that benefits the most from technical skill and access to specialized editing equipment and software. Although each participant was offered the opportunity to learn aspects of video editing—because of equipment demands and mobility constraints—the majority of the technical labor in this stage fell to me with assistance from Glen Ebesu, a professional editor. As my working collaboration with Glen grew, my collaborative research with Maria and Michelle was transformed. During post-production I made a concerted effort to sustain our collaboration by "outputting" rough

assemblages and meeting individually with Maria and Michelle to discuss our work-in-progress. In effect, during post-production, Maria and Michelle assumed executive responsibilities as co-producers providing notes and comments that guided my work during post-production. Though the labor of filmmaking throughout post-production is collaborative labor, my work with Glen focused on the technical editing of our footage, my work with Maria and Michelle focused on producing the film.

As part of the initial research design, I had intentionally emphasized during recruitment that we would be working together to create stories—a story, some stories—not *the* story of participant's lives and experiences. I wanted to make clear that our collaborative work was partial, situated. I sought to create overlapping stories[200] not master narratives. This clarity at the outset of our collaboration enabled young people to explore multiple storylines without the burden of defining a single story. As I assumed more of the responsibility for our collaborative labor in post-production, knowing that our stories were designed to be one of many helped me situate my work during this stage within the larger storytelling process and resist assuming a burden of representation.[201]

Post-production

Post-production is when much of the work begun in pre-production and production coalesce. It is a time when the multiple narrative potentials of any given story become realized, the result of incremental decisions made throughout our storytelling process that crystalize during post-production when we are forced to make narrative choices based on the materials

[200] Adichie, *The Danger of a Single Story*; Haraway, "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective."

[201] Chen and Morley, *Stuart Hall*, 263.

we have assembled or decide to return to production and reshoot or expand on segments that need further work. While production time can be calculated in terms of day and weeks, post-production is calculated in terms of weeks and months. For instance, Michelle's film required a total of 18 non-sequential days of production. By contrast it took six months to complete post-production on Michelle's film.

Post-production encompasses a variety of tasks. Figure 6.1 details the work we engaged in during post-production in order to complete our films. In post-production the collaborative workflow can be characterized as my collaboration with the editor that lasts the duration of post-production, and my post-production collaboration with youth participants that began approximately halfway through the post-production stage of each film. For example for Michelle's film it took me approximately 3 months to organize and prepare the footage in Avid in order to create a paper edit before Michelle and I could begin our collaborative post-production work.

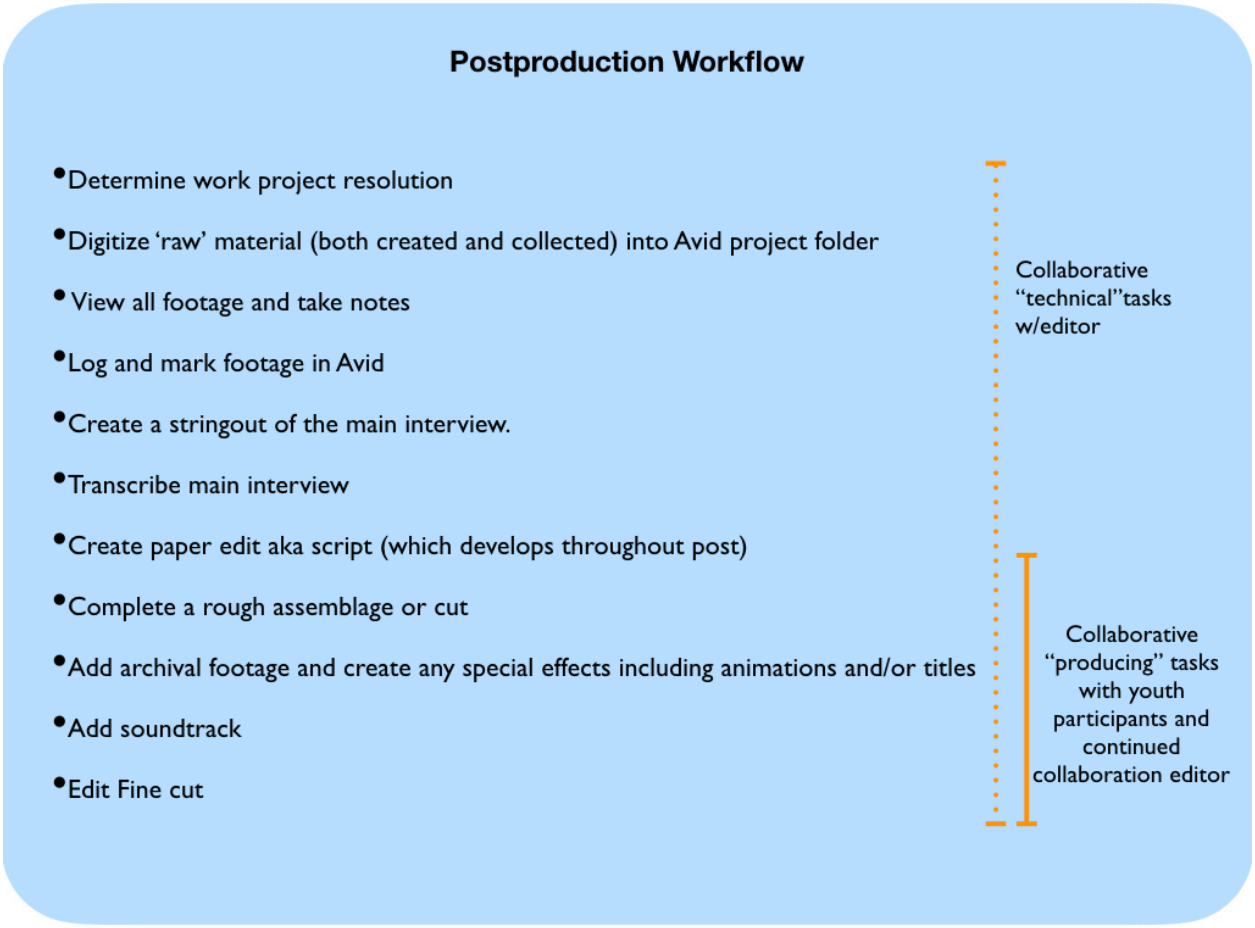

Figure 6.1 Post-production workflow

Collaborative "technical" tasks

1. Determining the final format.

Determining the final resolution, or look of your film, is one of the key decisions to make as early as possible in your project. Yet for independent filmmakers these decisions are typically aspirational, dependent on access to resources, including storage and processor capacity, factors that are both variable and untested prior to post-production. Our films were meant to communicate to an audience of Maria and Michelle's peers. Participants were taking a risk in sharing their stories by allowing others to view, learn and pass critique on their lives. As their

teacher, co-participant, and collaborator, I wanted participants to see their films and gain a sense of accomplishment in their stories and in our work together. Therefore, early in the project I decided to make the films look as professional as possible by filming in a high-definition (HD) format. This meant using the consumer-level HD equipment I owned for all team created material. However, archival images and youth-produced media were created using tools participants had available to them and were not necessarily delivered in HD. This resulted in source material across a wide variety for digital and non-digital formats.

2. Digitizing, organizing and managing material

One of my first tasks in post-production was transcoding all the video and archival images into the project resolution. In addition, we often had three sources of audio streams from our team produced material (from the DSLR and GoPro cameras and from the LAV microphone connected to the Zoom H1 audio recorder). These three audio streams all needed to be synced to our main video. As a result digital management, outside of any aesthetic consideration, became an important task.

Transcoding, or the process of transferring all the materials assembled in production into a shared project format should be a straightforward process of machine translation. Yet because many of the raw file formats are proprietary, transcoding can be and was a challenge. I was fortunate in my work to have the assistance of Glen. His expertise and artistic input was essential to the completion of our films. His experience with Avid, a subscription-based professional editing software for the Mac platform, facilitated much of the initial technical setup allowing me to import and transcode the media into a single system.

All footage was imported into the AVID at the start of post-production. However, reshoots, archival images or video effects (VFX)—like animations—were added as these

materials became available. For perspective, an inventory of the raw materials we created, collected and culled for Michelle's film is described in Table 6.1.

Table 6.1 Description and Ratio of Material from Production to Final Film

RAW MATERIAL BY TYPE		PRODUCTION		POST-PRODUCTION		FiNAL HD FILM
Produced by:	Footage type	Production time	Data quantity	Post production footage TRT (hr:min:sec)	Transcribed Footage TRT	
Team	Main interview and b-roll	6 hours	31 files, 61.94GB	1:30:22	49:00	
	How-To sequence	3 hours	29 files, 19.81 GB	1:36:35	~6:00	
	B-roll - Backplates	1 hour	18 files, 4.08GB	12:24	0	
Michelle	B-roll	15 days*	35 files, 4.62GB*	43:04*	0	
Archival stills	B-roll	n/a	13 files,14.6MB	6:30	n/a	
Subtotal		18 days	126 files, 90GB	3:26:36	0:54:00	
Final						9:57 TRT (20:1 ratio)

*These figures do not include videos Michelle created that were collaboratively screening and discussion but not used during post-production
TRT=Total Running Time

There were a total of 18 days of production for Michelle's film. Most of those days were partial days, in other words we did not work 8-hour days. Travel time is not included in the calculation.

The bulk of our material was created during team production of our main interview and b-roll. In addition, we had two follow-up joint production days during which we filmed an instructional "how-to" segment as well as additional b-roll and a separate day of production to film backplates. This involved filming Michelle in a specific location usually on a fixed tripod and then filming a "backplate" from the exact same position of the exact same location without Michelle in the camera's frame. Additionally, Michelle filmed b-roll over 15 different days of production according to the encoded information on her video files. Many, though not all, of her clips were short segments lasting under 1 minute. Many of her video files were filmed in a lower resolution than our project HD. Overall we had a shooting ratio of approximately 20:1, twenty minutes of raw production footage for every minute in the final film.

Once all the footage was transcoded into Avid, I was able to view the material in its entirety. I then began to take notes on the footage. These notes were decisions about the footage based on aesthetic and content quality. I created a log of the footage in AVID (see sample in Figure 6.2) marking segments I thought were important to the final film.

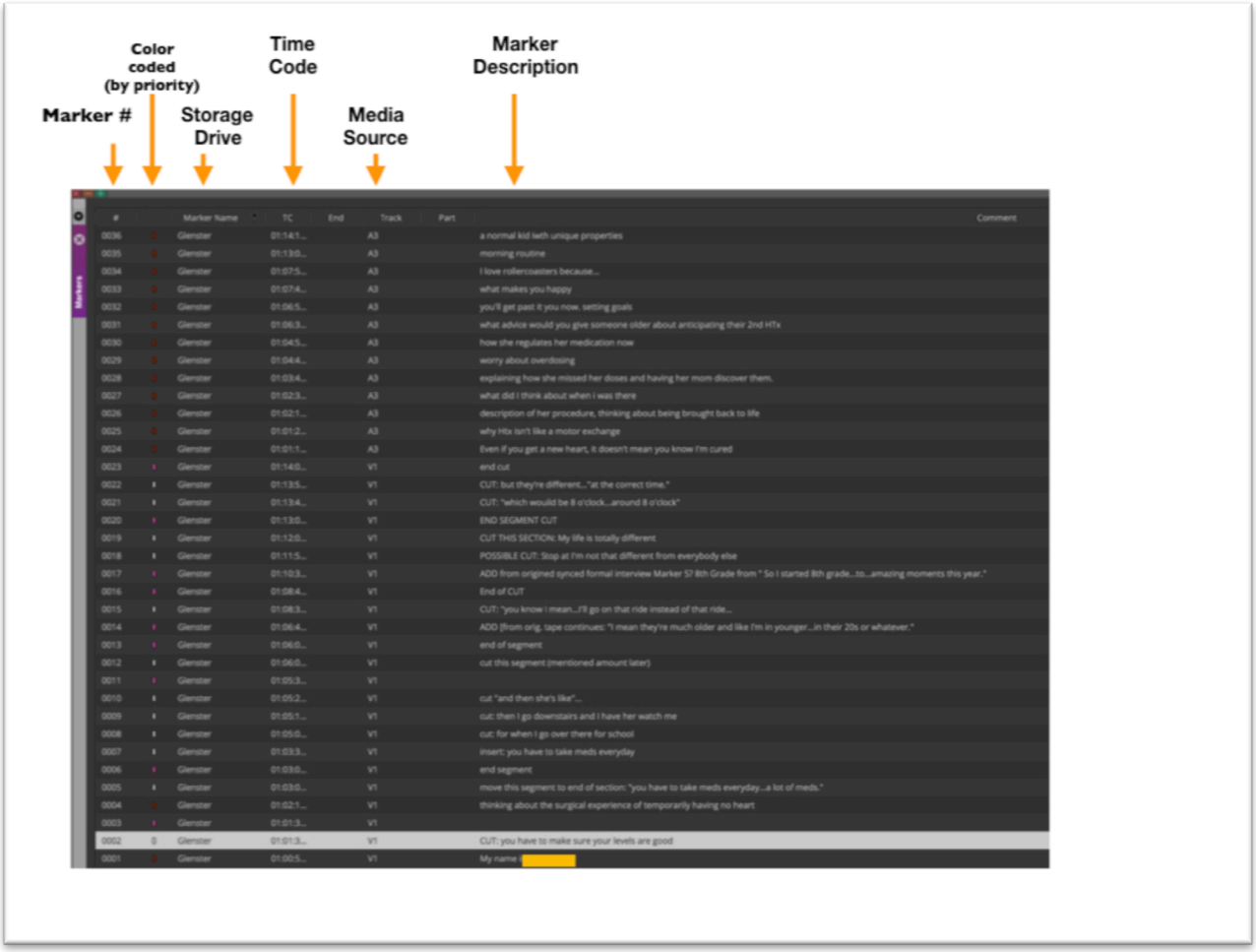

Figure 6.2 Example of Markers Report in Avid

These crucial organizational steps allowed me to digitally locate and organize footage based on the storyboard outlines that were collaboratively created.

3. Main interview stringout, transcript and paper edit

Next, Glen and I created a stringout of our main interview files. A stringout is simply when each video file is edited together chronologically into a single sequence. At this stage there is no editing of content, simply each digital file is linked together. I then transcribed this interview stringout. The working transcripts included multiple takes, multiple narratives and

multiple answers to a particular question, but eliminated "bad" production video or audio such as takes where I inadvertently hit the tripod and the image became unsteady.

These initial transcripts were rough transcripts meant strictly to help me create a paper script from which to edit our film. For Michelle's film, I typed the transcript using a combination of InqScribe and MS Word for Mac software. For Maria's film, I experimented with a low-cost online transcription service (Temi.com) that automated the transcription of audio files. These transcripts needed significant editing, and attention in order to transform them into usable transcripts.

Once transcripts and stringouts were created, I was able to then draft a paper edit of our film (see Figure 6.3).

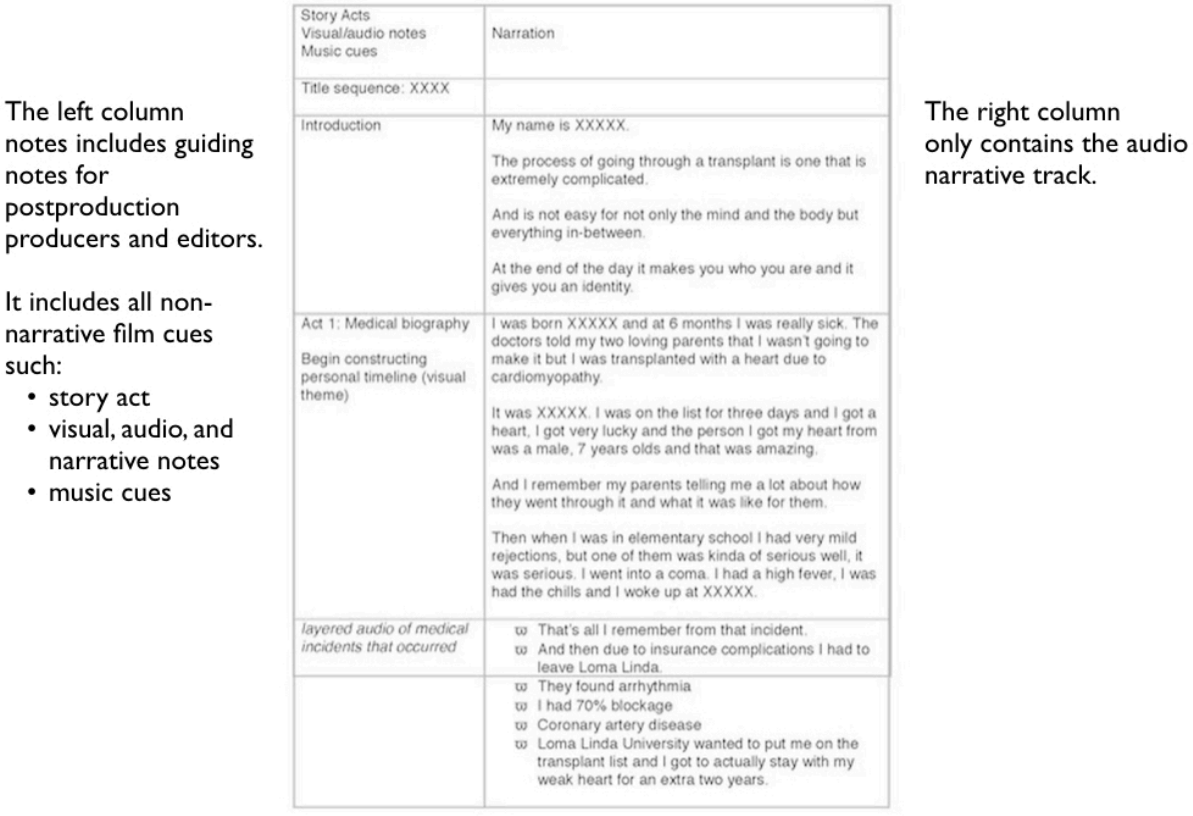

Figure 6.3 Page from a paper edit (identifying names and locations have been removed)

This sample page displays the two-column script that includes visual and non-narrative audio content in column one and narration in column two. Together this two-column script helps the post-production team orient the script to the film. The film-in-progress remains the main reference point. Though each initial script was crafted to hew closely to our co-created storyboards (see page X) editing choices are already embedded in this first draft. Decisions such as which is the best take of a self-introduction has already been made and is often dependent not only on what is said by the interviewee but by background action or noise. Did a motorcycle drive by and obscure audio? Did a sudden wind cause noticeable movement?

Only after I had completed these post-production steps did I begin to report back to Maria and Michelle to share our progress and challenges moving forward. With a paper script as our reference, I began to create rough assemblages from our footage, thus enabling the resumption of semi-regular team meetings to discuss and screen sequences.

4. Collaborative post-production meetings

Post-production meetings were opportunities for Maria and Michelle to learn how to produce a film. In our meetings at this stage, we would screen short visual sequences I had assembled based on the paper script and discuss what resources we had to tell the story visually or what changes and edits could be made to the narrative to conform to the material we had available. For example, Maria and I had discussed and decided to keep open the possibility that we might want an additional day of filming. It was only after we screened a rough cut of our film that we determined further filming was essential to complete the story we wanted to tell. Those aspects of executive decision-making and fine-tuning are professional producing skills which Maria and Michelle were able to learn during post-production.

One observation I noted as I began screening sequences with both Michelle and Maria was that there was a need to adjust to seeing themselves as subjects in our film. For example, here is a graphically modified photograph from one of my first screenings in post-production (see Figure 6.4). I have altered the photograph in an effort to protect the participant's privacy.

Figure 6.4 Reaction to first viewing

In this photo the participant is seeing her on-camera interview for the first time. Although she had participated in the set-up during production; had selected the site; had even looked through the camera's viewfinder after it was set on its tripod, this was the first time she saw how the camera recorded the setting with her in it. In the photograph she is holding her hands to her cheeks not in sudden shock but to contain and perhaps feel her own smile. She is beaming in the photograph. A similar reaction occurred during both initial screenings. I interpret these reactions as reflecting each participant's need to adjust to seeing themselves on film. But

I also interpret their reactions as direct expressions of pleasure in seeing their stories in the context of our production. As they gained familiarity with the footage and with the practice of screenings these initial reactions were supplanted by more editorial viewing of the sequences. Nevertheless their initial responses to seeing the results of our work were thrilling and informed my continued sense of responsibility and commitment to our collaborative relationship.

Collaboration through the editing process

5. Co-producing in post

Even though I had professional experience producing narrative sequences in post-production, the process of teaching and co-producing segments was a learning process for both youth participants and myself. Once Maria and Michelle worked through their own reactions to seeing themselves on camera, we were confronted with a series of narrative choices that required us to make editorial decisions in order to proceed. As a practiced producer, I knew issues of tone and story emphasis were dependent on small nuances of timing. Still, I struggled eliciting decisions from either Michelle or Maria in the early stages of screening and grew somewhat frustrated struggling to teach this aspect of filmmaking. It took me considerable time to understand that their minimal comments were not a reflection of either disinterest or being overwhelmed by the editorial challenge. Rather, I had failed to contextualize the editing process. The early sequences I focused on in editing were simply peripheral to, not the center of their narrative intent. In stringing together storylines I focused on the building blocks of storytelling and the easiest aspects of editing. Sequences like personal introductions, "Hi my name is..." or the use of b-roll to transition between segments of narrative interviews, were digested as ancillary, necessary perhaps, but subordinate to their central narrative point. Instead they screened the edits with a laser concentration on getting their story right. For example when I shared an underwater opening sequence that was technically challenging to

produce because it involved editing against one of the participant's favorite songs and included difficult graphical elements to make, I was certain that their reaction would be overwhelmingly enthusiastic. I assumed that my labor would be recognized. Instead, although they were certainly appreciative, they saw the sequence as a precursor to the main story. As producers what they rightly cared about was not from the quality of the technical labor involved. Rather they asked, did the sequence convey their central argument or point? Did their film reveal the challenges, the frustrations of being apprehended as delicate, deficient, wanting? Did the film show their capabilities, their expertise and labor in caring for themselves, their resilience? For instance, during production and post-production Michelle and I screened multiple versions of an important storyline. Together we discussed both her camera perspective and the movement of items within an image frame (see Figure 6.5). Because Michelle deemed this sequence such a vital story element, she filmed the entire sequence multiple times, refining and reworking her filming styles throughout production. Still, as I assembled this sequence and we began screening the results, we realized we had problems with story continuity. We determined that we would reshoot the segment in its entirety. As we discussed and prepared for additional filming, Michelle was keen to teach me the movement of her work so that I, as a camera operator, would be able to capture her actions.

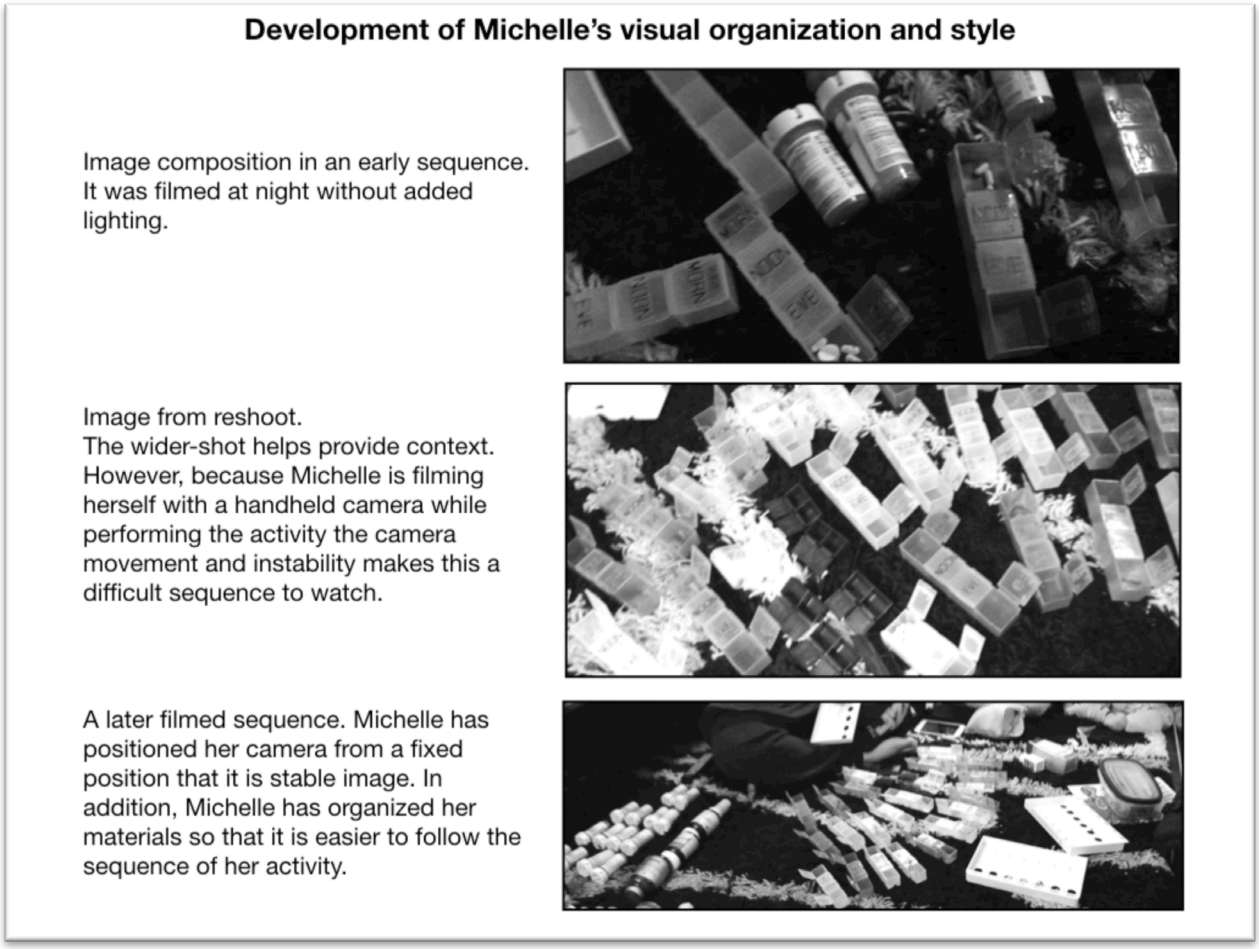

Figure 6.5 The development of Michelle's visual organization and style for filming a sequence

Through our collaboration, we moved from my teaching Michelle image composition in production (Figure 6.5), to Michelle teaching me the choreography of her movements in post-production (Figure 6.6).

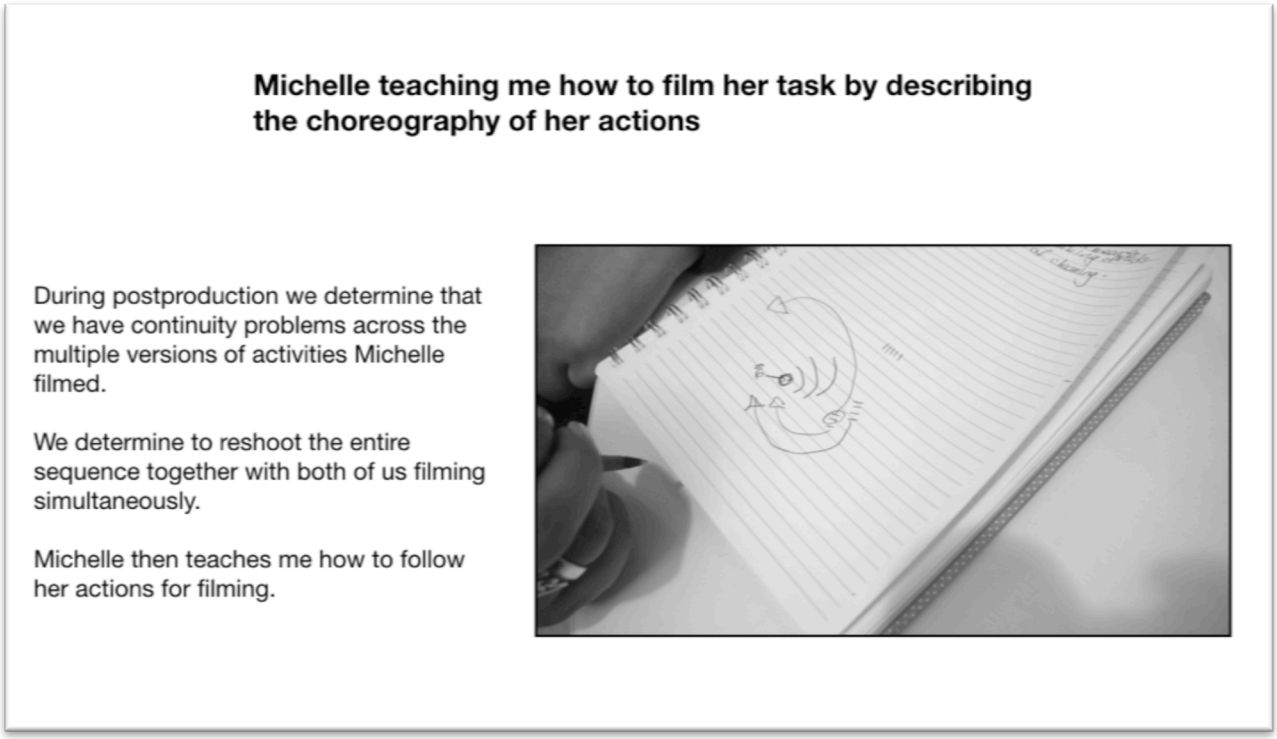

Figure 6.6: Michelle teaching me the choreography of her actions.

What I initially interpreted as a teaching challenge in post-production was in fact, a consequence of my own misunderstanding. What I learned in this stage of our research was to recognize my own learning needs and understand that both Michelle and Maria had assumed the role of producer long before I recognized it. During post-production while I was caught up in the minutiae of a cut, they never mistook the trees for the forest; the edited sequence for the narrative whole. In this way we worked through post-production together efficiently, stratified by responsibilities and each contributing essential labor in maintaining the quality of our work.

6. From Rough Assemblage to Fine Cut

As Maria, Michelle and I evaluated sequences, I also worked with Glen who transformed our rough assemblage to a fine cut. As a skilled editor Glen helped us both clarify and simplify story points. In addition to refining my rough cut, Glen was able to create both story, visual and

music transitions that seemed effortless in retrospect but required great skill. He and I also worked together on visual effects (VFX), sound effects, as well as a music soundtrack. The end result of our work is a multilayered digital file. Figure 6.7 is a screenshot of a one-minute segment of time code from Maria's film. It shows how the materials are interlaced together. Starting from top to bottom, there are three layers of video (V1, V2 and V3) and six layers of audio (A3-4, A9-10, A11-12).

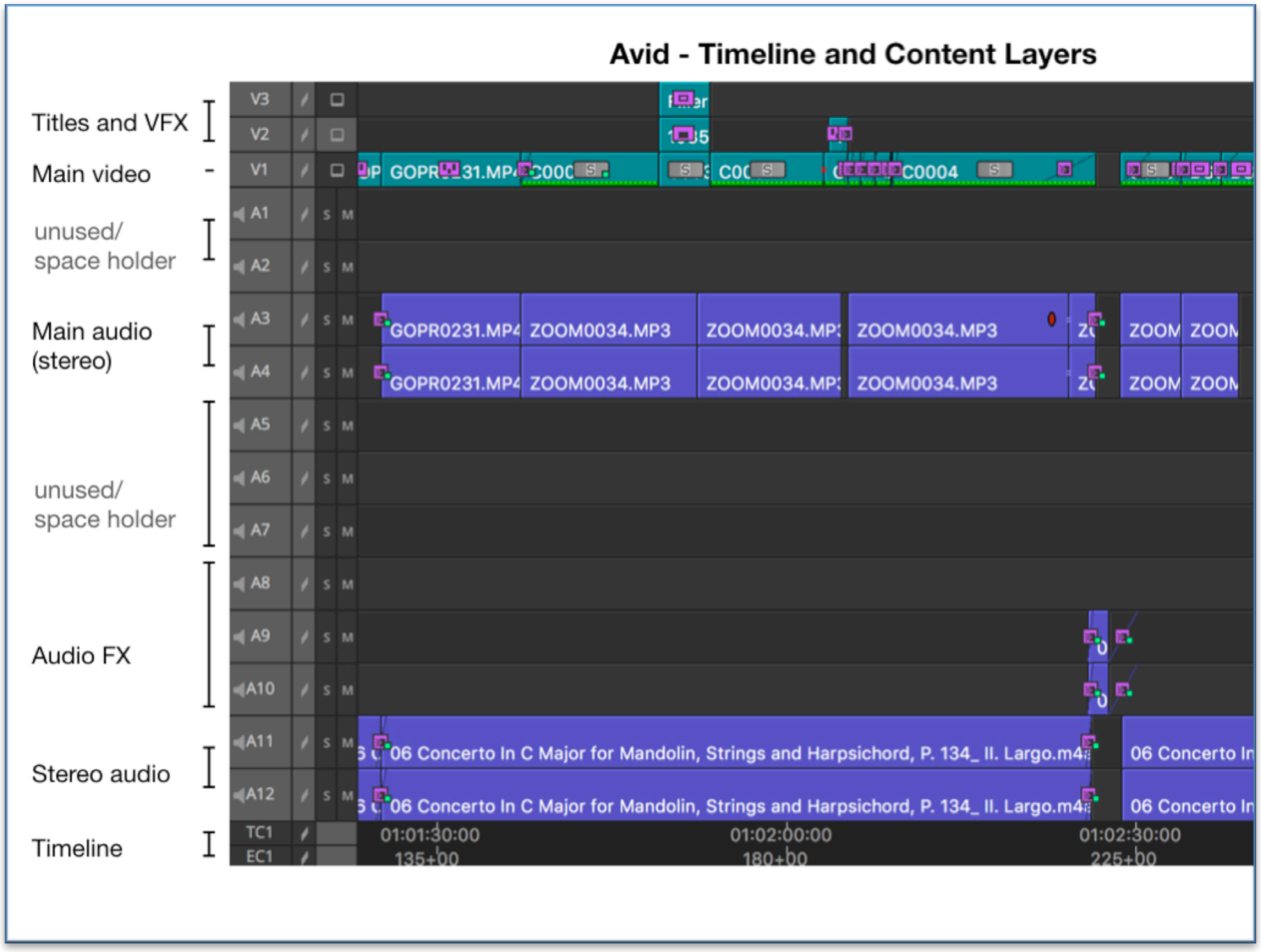

Figure 6.7 Detail from a 1-minute segment of AVID timeline

Video:

The layer labeled V1 is the main video content and includes video media we created during production. Layers V2 and V3 indicate video content that was built within AVID and its affiliated

software. These materials include items like titles (both main and segment title), lower thirds (a graphic overlay of location or speaker's name that is placed visually in the lower third of the screen), and VFX.

Audio:

Each audio layer is one stream of a stereo audio file so that A3-4 is the stereo content and main audio source synced to V1. As you can see in Figure 6.7, these layers included native audio (such as audio recorded by GoPro) as well as synced audio (all files beginning with "Zoom"). Layers A9-10, like V2 and V3, are special effects layers and like their video counterparts include dissolves, fade-ins or fade-outs. Layers A11-12 are our music layers.

Music:

The music soundtrack is an incredibly important and undervalued tool in non-professional video production. Because we had no budget and did not prepare our films for broadcast media, we did not seek music rights. During production, I ask Maria and Michelle for a list of their favorite music artists and songs. The soundtrack for each film includes favorite pieces. More often, I built a temporary music library for each film based on what I could find and what our editor requested. If Glen asked for an acoustic guitar piece, I sought to find music online first, and then in from my own CD library, that might be suitable. Glen made the initial music decisions and though Maria, Michelle and I had responsibility for the final choices, it reflects how well our editor was part of our collaborative team that we never overruled his choices and on several occasions Maria and Michelle told me how happy they were with the musical choices that were made.

The final two layers of any Avid Timeline window are the TC1 (timecode 1) and EC1 (edgecode 1). Of these layers only TC1 provided relevant information for this project and was used to sync segments as well as provide the total running time of each film.

Once we produced a fine cut, we were able to output and screen our film together for a final time as a work-in-progress. In these last meetings as a collaborative team, both Maria and Michelle brought a trusted friend or family member and shared our work with them. There was a tremendous sense of shared pride and accomplishment even as we each had personal goals and objectives in our work together. After these final meetings, each participant received a copy of the film and we began screening it jointly with medical caregivers, researchers, educators, and students as well as individually with friends and families. This marked the end of our collaborative project even as we kept open the possibility of further collaboration through future screenings and educational workshops.

Part Three

Chapter 7 - Visual Storytelling as Transformational Pedagogy

Youth Participatory Action Research

Scholars engaged in YPAR link their work to pedagogies of transformational resistance.[202] Often YPAR focuses on issues of social and educational inequity. Through inquiry-based research, YPAR enables young people to utilize their experiential knowledge to gain critical insight.[203][204] Though some, citing Gramsci, describe YPAR as accessing the "organic intellectualism" of youth,[205] it is the engagement with critical research that is the engine of transformation. For Cammarota, it is YPAR combined with a critical lens focused on social reproduction and the reproduction of "docile bodies" that has the "potential to transform young people's subjectivities."[206] Though scholars like Eve Tuck highlight the collaborative relationships between intergenerational researchers[207] often, at the center of YPAR is the figure of an activist scholar searching for a transformational pedagogy that enables and builds communities of critically engaged youth scholars. To these aspirational stories I add another. For what has been

[202] Cammarota, "Youth Participatory Action Research: A Pedagogy of Transformational Resistance for Critical Youth Studies"; Tuck and Yang, "Youth Resistance Revisited"; Solorzano and Bernal, "Examining Transformational Resistance Through a Critical Race and Latcrit Theory Framework."

[203] Tuck, "Theorizing Back: An Approach to Participatory Policy Analysis"; Solorzano and Bernal, "Examining Transformational Resistance Through a Critical Race and Latcrit Theory Framework"; Cammarota and Fine, *Revolutionizing Education*.

[204] The link between pedagogies of transformational resistance that emerge from experiential knowledge and research is linked to black feminist standpoint theory first proposed by Patricia Hill Collins and further elaborated by one of my teachers, Sandra Harding (see *The Feminist Standpoint Theory Reader*.)

[205] Caraballo et al., "YPAR and Critical Epistemologies: Rethinking Education Research."

[206] "Youth Participatory Action Research: A Pedagogy of Transformational Resistance for Critical Youth Studies," 189.

[207] Tuck, "Theorizing Back: An Approach to Participatory Policy Analysis."

crucial to this study is the recognition that teaching and learning are part of an ongoing continuum where expertise shifts back and forth across generations and individuals.

Rather than teaching youth about research, oftentimes, youth taught me. For example, a guiding research question I have asked in this study was what stories did young people growing up in high-tech medicine identify as important to share. When I asked Maria and Michelle this question their responses were varied, expansive and attuned to the interests and lives of each participant. Yet, as we began our collaborative video production a common theme across participants emerged, one which highlighted medication management as a central challenge and practice of daily life.

Michelle and I had completed our film together before Maria and I started pre-production. When Maria and I began to discuss specific story ideas to work on her very first story idea was, "I was thinking maybe medication would be the most important thing to focus on" (see Chapter 5). Yet, even as Maria spoke, the producer in me listened cautiously, worried that Maria's film would duplicate parts of Michelle's story. My reaction came from my training in television, a desire and need to differentiate, to specify uniqueness. In the context of research, what limited my imagination so?

Vivian Paley, whose work with young children led to the development of storytelling curriculum in preschools, emphasizes the importance of listening in teaching. Paley describes how, despite multiple opportunities and instances, it took her years to realize important themes in young children's stories. The example she gives is a growing awareness that only after hearing countless tales about birthdays did she come to understand that for preschool children the concept of 'birthday' was a "curriculum in itself."[208] Young children's stories about birthdays, about what it signified, how it was celebrated, how their birthdays differed from their parents...

[208] Paley, "On Listening to What the Children Say."

all these tales were occasions to share, celebrate, learn, and tell stories about birthdays to one another. Only after reading Paley's work did I begin to recognize that for the adolescents and young adults, who so generously shared their stories with me, 'medication' was a curriculum in itself. When Michelle and Maria first told me they wanted to tell stories of medication, I heard and understood one thing, yet I came to understand that their stories were multifaceted, rich and complex. They told stories about medication management that extended across hourly, monthly and yearly timescales. They described the accumulated costs and complexity of medicine which, even as it is an existential necessity—it prevents their own body's rejection of their donor heart— it is also, cumulatively, a toxin that damages other bodily organs and necessitated multi-organ transplants and further hospitalizations. By insisting that medication was curriculum both Maria and Michelle were able to position their management of medication as a practice of self-care moving beyond a framework of medication as something imposed upon them by authority figures, part of the adult policing of their bodies and behavior.

Storytelling as transformational pedagogy

By sharing stories, Maria, Michelle and I taught each other about medication, about visual filmmaking, about living in spaces of precarity. We taught each other, and just as often we taught ourselves through critical reflection. Storytelling offered us all an opportunity to build stories and contemplate our past, present and future.

Once we completed the films I asked both Maria and Michelle to identify what they learned in the process of our collaboration. Maria reflected that she learned that "keeping my health is a lot of work." Michelle wrote;

> During the process of this film I have learned multiple things about myself as a transplant patient. I never actually sat down and thought about how my

transplant has affected my life and the fact that there are others out there that are like me but are struggling on how to deal with their chronic illness.

What became apparent was that the opportunity to tell stories enabled both Maria and Michelle to step out of the rigors of living in clock time to recognize their success in caring for themselves. It helped transform how they positioned themselves in the present by enabling them to recognize their expertise and place themselves within a community of others struggling "with their chronic illness."

Our films were designed to be shared and because of this I asked Maria and Michelle what they hoped their audiences would take away from a viewing. Michelle wrote that one of her hopes was that the film would help patients and family caregivers address fears of "what their life will look like after their transplant." In identifying the scope of our films, Michelle is describing the horizon of a before and after. Before, for many pre-transplant patients and families, is a known entity. It is living with chronic heart failure. What comes after, however, for each individual and their families is unknown even as it is laced with a promise for a new life. In sharing her story, Michelle is offering them one embodied account of living with a transplant.

Maria wanted her film to address her Middle School classmates and teachers. When I asked her what she hoped they would learn from viewing her film she wrote, "I think they would have a better understanding of what I go through everyday even though I look really healthy. They don't have to be afraid to have me do stuff." Maria is pointing to a common problem for people with invisible disabilities. They look healthy. Through her story Maria shows how heart transplantation continues to impact her everyday life and confronts schooling practices that emphasize disability as a difference to be wary of: disability as something both unusual and dangerous.[209] In our film, Maria attempts to shoulder the responsibility and bridge

[209] De Schauwer, Van De Putte, and Davies, "Collective Biography."

the disability/difference divide by showing her capacities and joy in physical activities—like riding rollercoasters—that many find daring and dangerous. Maria wanted to show that even as she needs support with medication management during field trips, teachers do not need to exclude her from activities or class rewards, like fieldtrips: [210] "they don't have to be afraid."

Moreover, our storytelling research enabled both Maria and Michelle to position themselves as experts vis-à-vis medical professionals who, like their parents, are figures of authority crucial to their ongoing care. Both saw their stories as providing doctor's another glimpse into the lives of patients and families outside clinical settings. Maria wrote that she hoped her film would give doctors the ability to "see from a teenagers point of view how hard & how much heart transplants effect our lives." Movingly Maria writes about her hope that healthcare professionals, "learn that you still wanna be a normal child & that you will struggle with many different things & we need mental support." Perhaps some may read this as nascent expressions of transformative subjectivities, yet being able to insist, *these are my experiences, these are my desires,*[211] *and these are the types of healthcare support I need,* are significant interventions to authority figures that can help create supportive bridges in transitional medical care as well as in the transition to adulthood.

Research as Empowerment

By telling their stories Maria and Michelle sought to build affinities and alliances, they sought to build communities for understanding. Even so, in their efforts to bridge

[210] De Schauwer, Van De Putte, and Davies.

[211] Feminist scholars especially in media studies have long interrogated desire as sexualized desire. Eve Tuck and Erica Violet Lee offer different perspectives positioning desire as an agentive alternative to damage-centered research Tuck, "Breaking up with Deleuze"; Lee, "Wīhkohkē: Urban Indigenous Resistance from the Past into the Future."

diversity/difference they were confronted by embedded frameworks that underscore their differences with powerful implications.

I began this study highlighting transition in transplant medicine as an ongoing care and concern, a focus due to increased mortality rates just when young people are transitioning to adult medical care. I end by showing how, even in healthcare practices that occur within medical and cultural logics of care and caregiving[212] like those that both Maria and Michelle identify as their experiences of healthcare, normative practices engage in excluding young people as competent participants in the care of themselves.

For example, on the last day of our extended production period, when Michelle and I were still searching for an ending to our film, Michelle spoke about her the results from a recent clinical checkup:

29.	Michelle	going to the doctors appointments is hard Uh i
30.		just went last week i think and i miss work
31.		~because i had to stay there all day but
32.		hopefully- and all the test results came back
33.		positive
34.		i am doing gREAT and so ~it was worth it knowing
35.		that I'm not doing anything wrong
36.		(h) so it's a good thing
37.		going to the doctor's appointments
38.		having surgery

In lines 34-35, when Michelle speaks about "doing great," she is referring to her test results indicating her general as well as her heart's current health status. But what does it mean when,

[212] Mol, *The Logic of Care*.

in hearing good news: "I'm doing great," Michelle immediately translates that into "I'm not doing anything wrong"? What does it mean when Michelle has internalized her decisions as either *doing* or *not doing* something wrong?

Within the normative practices of medical care Michelle's "I'm not doing anything wrong" can be understood as her response to a culture where the language of (non)compliance and (non)adherence replicate power relations that objectify the lives of young people by inscribing designations of disability/difference into the very interpretation of a medical test result that denies Michelle's agency in contributing to her own care. In this logic, Michelle is doing great because she has not done anything wrong, not because she is doing everything right.

This passage is a reminder that critical disability studies challenges us to "rethink the relations between disabled and non-disabled designations — not just ethically as has long been the demand but ontologically, right at the heart of the whole question of self and other"[213]

Here I invoke the work of Zoë Sofoulis as an alternative model for thinking through transition. Building from Gregory Bateson's ecological thinking,[214] Sofoulis offers the metaphor of "knowledge ecologies" as a way to describe sustainable models of community that recognizes multiple inhabitants as part of a knowledgeable ecosystem. Knowledge ecologies "implies groups of diverse players of different sizes and roles, each finding their niche in a system of knowledge flows."[215] By seeking the spaces-in-between adults and adolescents, normativity and difference/disability within a knowledge ecology focused on sustenance and survival it becomes apparent that the language of (non)complicance and non-adherence situate young people as hindrances to their own care.

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[213] Shildrick, "Critical Disability Studies," 30.

[214] Bateson, Gregory, *Steps to an Ecology of Mind*.

[215] "From Integration to Interaction"; Sofoulis et al., "Coming to Terms with Knowledge Brokering and Translation. A Background Paper."

Our storytelling research counters this discursive net and reveals young women highlighting the complexity of medication management. Rather than exacerbating power differential across generations and medical authority, their stories transform medication management from a logic of power and the policing of their bodies and behavior, and into a logic that, even as it recognizes the difficulty of practice, positions medication management as a recognition that self-care is critical to survival.

At the start of this dissertation I asked what stories would youth participants think were important to share. I wondered what narratives would get chosen, discarded and revised. How these decisions would be made and, overarchingly, how was knowledge about living with heart transplantation constructed. These questions defy straightforward answers. I have endeavored to answer them through an ethnographic account of our collaborative visual storytelling process. This ethnography of learning reveals the complexity of thoughts, expertise, learning and practices in action.

Emergent topics for further study

This study opens multiple trajectories of further research opportunities. In this section I map the outlines of four research projects, with subsections, that I plan to pursue in the near future. These projects are all inspired from the dissertation research and continue my ongoing commitments to collaborative participatory research while extending the methodological repertories of inquiry to mixed method, multi-sited, multi-scaled studies.

1. The extension and expansion of collaborative visual storytelling research

The first research project is both an extension and expansion of my dissertation work. Part of my hope when constructing my research design was to hold multiple screenings of the

educational films Michelle, Maria and I created across a variety of audiences including screenings for family and friends, middle and high school classrooms and at healthcare sponsored workshops and outdoor camps designed to support transplant patients and their families. I wanted these screenings to provide an opportunity for Maria and Michelle to share their work as outreach in the context of team research. I also hoped to use the occasion as an educational opportunity to foster discussion and learn about organ transplantation. Although these aspects of my research design proved to be beyond the capacity of this current study, I believe the design is still sound and extending this ethnography to screenings with audiences would support this research in three key ways: 1) Using the screenings as educational and research opportunities would help identify and refine further means to support young people in transition. 2) Building on this study through continued screenings would also offer an opportunity to recruit and expand the number of youth participants engaged in collaborative storytelling research, thereby creating a body of educational films to support heart transplant patients in transition. 3) These screenings would also offer an opportunity to recruit and broaden the perspectives about growing up with a heart transplant by sharing the stories of siblings, parents, family caregivers and healthcare professionals.

A significant challenge to this research is the paucity of funding available for media and educational research studies and the significant costs for professional production. In a meeting with a representative of UCLA's Office of Corporate, Foundation and Research Relations, Professor Raia and I were explicitly told that we were unlikely to find research foundation grants for video production projects. However California Humanities does offer a California Documentary Project (CDP) Grant for Film, Audio and Digital Media. Though funding is limited,

a CDP would allow me to expand the film project, perhaps long enough to complete a documentary short for distribution by public television on their POV[216] (point of view) program.

2. Longitudinal Study

This dissertation focuses on coming of age as a transition from adolescence to adulthood for youth who received heart transplants as children and are transitioning to adulthood and adult medical care. As part of an emerging cohort of young people living in the interstices of biotechnological innovation, Michelle and Maria provide unique insight into the challenges of growing up with heart transplants. Another possibility for research is to engage both Maria and Michelle in longitudinal studies of the ongoing challenges and transitions they face in caring for themselves throughout their lives. This research could utilize visual methodologies but, depending on funding sources, could also engage in other research methods including oral history interviews.

3. Oral life history of pediatric heart transplantation and transition

Another project that utilizes my training in historical research is an oral life history of pediatric heart transplantation and transition. Under the framework of science sciences, an oral life history of pHTx could document and examine issues of biotechnological innovation, the history of heart transplants as care continues to evolve, issues of ethnicity, class, culture and gender in the context of the organ donation; as well as in the context of workplace and home environments. There are several historical organizations that provide funding for oral life history projects. However like other oral life projects conducted in science studies,[217] I would approach

[216] POV, *POV - Acclaimed Point-of-View Documentary Films | PBS*.

[217] Murillo et al., "Partial Perspectives in Astronomy"; Holbrook, Gu, and Traweek, "Reaching for the Stars Without an Invitation."

professional organizations like the International Society for Heart and Lung Transplantation for support of this work.

4. YPAR as transformation pedagogy

A different research trajectory could seek to build a knowledge ecology framework focused on YPAR as transformational pedagogy. This project would highlight youth voice—not as a monolithic voice, but as a generational one—in order to examine how young climate activists are linking the current global health crisis to the climate change crisis and to economic precarity. Working within an ongoing collaborative research team based at the University of California at Irvine examining climate change within the framework of disaster studies, this project could highlight youth voice—not as a monolithic voice, but as a generational one—in order to examine how young climate activists are linking the current global health crisis to the climate change crisis and to economic precarity. Threading this work through multiple frames of disaster studies, this multi-sited ethnographic project would examine youth climate activism through the framework of knowledge ecologies to understand the ways in which diverse groups navigate the challenges of attending to climate change while engaged in building an intergenerational, multicultural movement with scientists, local activists, and transnational groups. Youth activists who have been striking in person on Fridays for over a year, immediately called for adapting and changing behavior and moved to climate strikes online. I see this project as an ethnography of student activism that mobilizes educators, scientists and communities to situate their expertise as a transformational pedagogy to effect governance policy change.

Conclusion: Stories of Survival

And Polo said: "The inferno of the living is not something that will be; if there is one, it is what is already here, the inferno where we live every day, that we form by being together. There are two ways to escape suffering it. The first is easy for many: accept the inferno and become such a part of it that you can no longer see it. The second is risky and demands constant vigilance and apprehension: seek and learn to recognize who and what, in the midst of the inferno, are not inferno, then make them endure, give them space."

—Italo Calvino, *Invisible Cities*[218]

This collaborative visual storytelling research has sought to highlight the power and possibility of storytelling for young people who received heart transplants as children and are in transition to adult care and adulthood. In doing so I teach and share from many pedagogies and traditions of storytelling. By giving voice to stories we discover our capacities and indebtedness to one another in the activities of listening, telling, teaching and learning. In this research Michelle and Maria share stories of their survival. Maria and Michelle are part of a unique community. They are young women, among the first generation of young people, living into adulthood in the aftermath of organ transplantation. Through this collaborative project they share their expertise and techniques for surviving in the interstitial spaces of high-tech medicine while learning about visual storytelling through the production of educational films.

This dissertation is an ethnography of our teaching and learning together. Anthropology has a history of objectifying other cultural forms and practices. Embodied in this dissertation is

[218] *Invisible Cities*, 165.

the recognition that collaborative research is a form of gift-exchange.[219] It is not simply a description of the cultural practices of others. It is a lens for situating research here and now and the complicated forms of exchange and entanglements embedded in collaborative work.[220] The films that we created and the findings from this study inform transformational approaches to communicating and understanding the experiences of young people in transition in heart transplant medicine. It also supports an educational philosophy that frames learning as a way of life.[221] Through the lens of teaching and learning I seek to build narratives of positionality, practice and pedagogy. It is my hope that this work helps build our capacity to recognize and enable spaces and communities for the many youth coming of age in the transitory spaces of modern life.

[219] Mauss, *The Gift: The Form and Reason for Exchange in Archaic Societies*.

[220] Lebra "An Alternative Approach to Reciprocity1." analysis of reciprocity as gift-exchange across differential power relations, what he terms "asymmetrical strains" is also pertinent to YPAR studies.

[221] Hadot and Davidson, *Philosophy as a Way of Life*.

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