

Beyond the Case

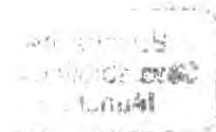
*The Logics and Practices of Comparative
Ethnography*

Edited by

COREY M. ABRAMSON AND NEIL GONG

OXFORD
UNIVERSITY PRESS

2020



Using Computational Tools to Enhance Comparative Ethnography

Lessons from Scaling Ethnography for Biomedicine

Alissa Bernstein and Daniel Dohan

Introduction

Ethnographers have long been drawn to thinking about how to compare and the logics of comparison: what makes cases, places, ideas, or concepts comparable or incommensurable, who compares and how, and how can comparisons be best represented (Lock 2002; Marcus 1995; Maurer 2005; Kleinman 1978; Ong and Collier 2005; Ragin and Becker 1992; Small 2009). In this chapter we consider approaches to enrich ethnographic methods through transdisciplinary influences that foster a dynamic engagement with comparison. These approaches reflect our grounding in ethnography as well as our daily encounters with biomedicine, an arena where ethnography has a rich history of impactful engagement with both scientists and practitioners. Our techniques incorporate computational tools that complement ethnography, but we emphasize their utility as methodological innovations within our particular research setting rather than as technical solutions. Our standpoint is that of ethnographers employed and embedded in an academic medical center, and our arguments in this chapter reflect our experience as ethnographers (from anthropology and sociology) in and of the medical field. As have past generations of ethnographers, we have found biomedicine to be a fruitful site for engaging in comparative ethnographic analysis. The innovations we describe here have fostered interdisciplinary engagement across the social sciences and biomedicine, and thus a central goal of this chapter is to share our experiences and reflections about how these computational tools have engendered this meaningful engagement. We consider the insights these innovations have provided on the variance of culturally

embedded practices across practice settings, patient populations, clinical conditions, and treatment modalities. We also consider the limitations of these methodologies and the ways in which they not only complement but potentially also threaten the ethnographic project.

The computational techniques we describe originated in biomedicine, public health, and geography, and we have shaped and extended them to inform comparative ethnography. Broadening the scope of ethnographic case analysis and data presentation enables researchers to more directly examine and interrogate the data, representation, and conclusions of an ethnographic study. We also suggest ways social scientists can benefit from engaging with models of science that extend beyond their disciplinary orthodoxies. Thus, while our empirical examples in this chapter are drawn from the fields of health and medicine, we see these techniques as potentially useful for ethnographers of other domains as well.

Medicine, Ethnographic Engagements, and Comparison

The practice of medicine depends on eliciting patients' narratives, and observational research has been a valuable tool in our attempts to understand and improve practice (Glaser and Strauss 1967; Bosk 1979; Timmermans and Shen 1999). Ethnography, which involves collecting narratives and conducting participant observation, is thus a potentially powerful tool for advancing research and, ultimately, improving practice. However, when it comes to shaping research and practice, researchers and policymakers typically turn to quantitative analysis. Qualitative methods are often seen as insufficient to advance scientific research and improve practice. Social scientific studies of biomedicine thus confront a quandary that resembles that which engulfed the social sciences broadly in the late twentieth century. In the 1980s to the 2000s, "quantitative" versus "qualitative" social science investigators wrestled over the legitimacy of these research approaches. In the social sciences, scholars became more comfortable with a pragmatic epistemology that focused on using either approach as long as it advanced understanding of significant theoretical and empirical questions. Quantitative methods remain dominant for a variety of reasons—they monopolize other fields of science, they are more efficient for making generalizability claims, and advances in computer technology has broadened the scope and power of numeric data

and analysis. Researchers often turn to qualitative methods when their goals are developmental or exploratory, such as refining close-ended survey items or mining focus group data to identify new concepts. In medicine, analysts appropriately note that such studies contribute to the field—and should be evaluated—in ways that are distinct from the hypothesis-testing or causally driven studies that typically use quantitative methods (Reeves, Kuper, and Hodges 2008; Devers 2011; Devers 1999; Kuper et al. 2008). This “exceptional” treatment afforded qualitative data brings ethnographers to the biomedical research table, but it brings them there as guests rather than as full scientific contributors. Medical anthropologists and sociologists who use qualitative data must still navigate epistemological tensions when they engage biomedicine.

One potential pathway to navigate this tension and legitimize qualitative methods in medicine is for qualitative researchers to develop new ways of plying their craft that speak to the culture of biomedicine while maintaining the integrity of their approach. In our work, we have found that our concept of what ethnography is, how it can be done, as well as the question of how to represent our work is fundamentally changing through our encounter with biomedicine in our role as researchers in a biomedical setting. This occurs both in the encounters we have in our research with the culture of biomedicine as well as our adaptation and incorporation of aspects of biomedicine’s methodological approaches, concepts, and technologies. In reflecting on her own work, anthropologist Marilyn Strathern (1988) critiques social scientists’ attempts to describe, understand, and analyze others through their own taken-for-granted disciplinary language and frameworks. These modes of thinking, she suggests, enter into researchers’ analyses, and become unquestioned assumptions (Strathern 1988, 9). Strathern suggests that a more fruitful starting point for analysis may be found in the expansion and extension of concepts that happens in the encounter between the researcher and the field. In our work, this encounter is represented through our interactions, as social scientists, with the fields of biomedicine that we study through ethnography. Biomedicine’s practices, concepts, and methodologies have fundamentally shaped the concepts and methodologies. As such, our way of doing ethnography reflects the culture of biomedicine and we in turn aim to intervene in and shape the culture of medicine. We have developed methodological extensions based on these encounters and the requirements of ethnography in a biomedical setting. Biomedicine has thus productively “elicited” methodological innovations from us in the realm of comparative

ethnography as we try to communicate, translate, and scale ethnography for biomedicine (Strathern 1990, 201). Furthermore, our approach to ethnography must constantly change, adapt, and extend—both our methodologies and the concepts we use—through these encounters. In the examples we describe in this chapter we show how the methodologies we use have been infused with and reshaped by the language and tools of biomedicine and health.

The Ethnoarray: Increasing Ethnographic Accessibility and Transparency

Ethnographers who work with or within the medical research community recognize the need to bridge the scholarly divide between conventional ethnography and the norms of scientific scholarship. Qualitative social scientists educate their biomedical science colleagues about the insights that ethnography brings to their work, the distinct types of rigor which ethnographers bring to analysis, and how the epistemological foundations of ethnography stand in distinction to that of the natural sciences (Reeves, Kuper, and Hodges 2008a; O'Brien et al. 2014). This educational approach creates a bridge which some clinical and health policy researchers traverse to embrace ethnography.

Nothing prevents ethnographers from crossing the bridge in the other direction—toward the conventional science of biomedicine—and a number of notable efforts have been made to do so in recent decades. Ethnographers, familiar with the scientific critique of the method, do not lack for understanding of normal science. But their attempts at bridge-crossing have struggled to find theoretical and epistemological solutions that can link the ethnographic enterprise with conventional science at a more foundational level (Lamont and White 2008; Ragin et al. 2004). Meanwhile, the medical community has pursued technical and methodological fixes. When applied with an eye toward procedural orthodoxy—an orientation that disciplinary ethnographers who learned the ethnographic craft at mentor's knee may find anathema (Becker 2009). Ironically, grounded theory has provided the most common source of procedural orthodoxy in medicine. Biomedicine embraced the approach because it spoke to core substantive questions rather than for its ability to groundbreak new theory through application of humanistic phenomenology (Charmaz 1995; Strauss and Corbin 1990; Strauss

1987; Creswell 2007). An additional irony is that applied ethnography has moved into biomedicine along with computer-assisted qualitative analysis (Miles and Huberman 1994). Like grounded theory procedures, computer-assisted qualitative data analysis (CAQDA) enhanced the apparent rigor of ethnographic analysis. But as implemented, CAQDA actualized in software what ethnographers had done on paper for a century. This embrace of skeuomorphism meant ethnography missed out on a potential pathway by which technology could help cross the bridge to conventional science. If there is a common desire for a genuine link between ethnography and biomedicine, the results of bridge-crossing to date have not arrived there. For ethnographers, the status quo may feel frustrating. Biomedicine is using qualitative approaches to address the questions they care about, but despite repeated attempts, ethnographers have had limited success at reshaping the fundamental questions that are asked nor in redefining the rules for what counts as valuable evidence (Greenhalgh et al. 2016).

From this inauspicious starting point, we describe here a sense that elements are in place to create a more genuine connection between the ethnographic and conventional-biomedical scholarly enterprise. New approaches for sharing and displaying data have shown their capacity to advance the ethnographic project of sharing experience and illustrating culture. The alt-right and Arab Spring illustrated that the Internet has cut the Gordian knot of empowering previously muffled voices in ways unimagined by postmodern theory two decades ago. Academic ethnographers have found ways to visualize data in ways that bring readers closer to social dynamics that had previously been described through narrative and prose (Desmond n.d.). We argue here that ethnography can embrace methodological tools and paradigms that will allow it to share more of its narrative more transparently. Mostly what is needed is a CAQDA approach that breaks from previous skeuomorphism by using a different data analytic and presentation approach.

Origins of the Ethnoarray

As is common in science, the innovations to address these questions did not arise from an abstract desire to advance theory or method but rather from a practical problem. In 2010, we began a project to examine how cancer patients with late stage disease began enrolled in early-phase clinical trials for new cancer therapies (Garrett et al. 2017; Dunn et al. 2016; Koenig et al.

2015). In early phase trials, new treatments of unknown benefit are examined in humans. The patients who participate in these trials typically have terminal disease and may have suffered from cancer for many years and have tried many other treatments. They may be physically or emotionally frail. Early phase trials are small—enrolling as few as a one to two dozen patients nationwide—with stakes that are potentially considerable for pharmaceutical industry profits and cancer researcher careers. Early phase trials had already proven a rich ground of ethnographic exploration (Fisher and Kalbaugh 2011; Fisher, Cottingham, and Kalbaugh 2015; Petryna 2009).

Our applied setting and goals made a sociological approach to trials less than fulfilling. Our study promised to advance practical understanding of the early phase trials experience with an eye toward addressing the persistent challenge of recruiting patients to participate in these studies. This promise helped secure funding from the National Cancer Institute (NCI), which in turn helped establish our legitimacy at the clinics in which we embedded ourselves. A solo ethnographer might have been able to gain access to some of the field sites, but our focus on the medical community's problem of trials enrollment allowed us to place a team of ethnographers at multiple sites and thus collect data at a larger scale. The warrant for our study thus draws on Katz's insights about ethnography that provides a naturalistic approach on historically emergent or policy-relevant phenomena (Katz 1997). But our warrant was not to produce a study of interest to sociologists. It was to provide insights that the policy and biomedical community would find convincing and actionable, for example, what strategies do patients follow as they manage late stage disease and how can clinicians help patients make good treatment decisions given the patient's strategic approach to their illness experience (Garrett et al. 2018). It was that practical goal that led our research team to attempt a technological jump toward the biomedical research community by developing a different approach to ethnographic data management, analysis, and visualization.

Other disciplines have embraced new technological approaches for sharing and illustrating data with great vigor and less ambivalence. Biomedical research includes computer-aided representations of the microscopic world, and sharing data is the norm in the field—even if biomedicine is considered a relative laggard in developing the intellectual infrastructure to share data broadly as compared to fields such as physics and aeronautics (Stokols et al. 2008; Stokols 2006). In biomedicine, the sequencing of the human genome

played a role in advancing transdisciplinary team science, and coincidentally, a genetic analysis technology inspired our efforts to experiment with how a stronger embrace of technology might allow ethnography to move closer to biomedicine. The data management and visualization techniques used in genetics seemed able to address some of the challenges of qualitative research in biomedicine, including analytical and data transparency due to the large volume of data collected during qualitative research, the context of the clinical setting, and the need to preserve informants' identities. The approach, the ethnoarray, presents ethnographic data visually. It was modeled after the genetic microarray, a visual approach to data presentation and analysis developed by biologists. The logic of the ethnoarray itself, how it compares to other types of computational methods, and its empirical application, have been published elsewhere (Abramson and Dohan 2015; Abramson et al. 2018). Here we summarize its key features as a strategy for scaling ethnography for biomedicine.

In developing the ethnoarray through our encounter with biomedicine, we adopted the biomedical community's conventional definition of science—without impugning the legitimacy of the epistemological stance that grants conventional ethnography its scholarly, intellectual, and humanistic value. The ethnoarray accepts the need for data reduction and quantification, which provide a plausible pathway for making ethnographic data and analysis consonant with biomedical science norms. The ethnoarray uses thematic data coding of ethnographic texts for the purpose of data reduction. This is a standard procedure for many ethnographers, including those working in the tradition of inductive discovery such as grounded theory and phenomenology. The ethnoarray is a tool for comparative data analysis, so data coding may begin with induction and exploration, but it typically is not complete until analysts arrive at a more deductive coding strategy that can be applied across multiple cases. To this point, the ethnoarray is consistent with conventional ethnography, but it then departs. Analysts constructing an ethnoarray must deductively define what constitutes an analytical case and establish data categories and elements to apply to each case. Once analysts define consistent cases and data elements, statistical software can discover patterns in the coded ethnographic data using nonparametric techniques such as principal component analysis. The resultant patterns of cross-case similarity and difference can then be displayed graphically, as shown in Figure 8.1.

Figure 8.1 shows an ethnoarray based on ethnographic case studies of thirteen patients with advanced cancer. These patients were enrolled in a study that examined the reasons and pathways that cancer patients enrolled in clinical research studies, a focus that is reflected in the categories (e.g., role in treatment conversations, medical knowledge) and codes (high involvement, multiple consults, etc.) shown on the right side of the array. To simplify this array, its cells reflect merely the presence (black) or absence (white) for a particular patient (each represented by a single column and identified at the bottom of the array). To aid in the interpretation of the array, we used hierarchical clustering to order the patients based on the similarity of the thematic patterns in their case. Based on the results of the quantitative analysis, the patients were then sorted into two groups, Reliant Insiders (group A) and Active Outsiders (group B).

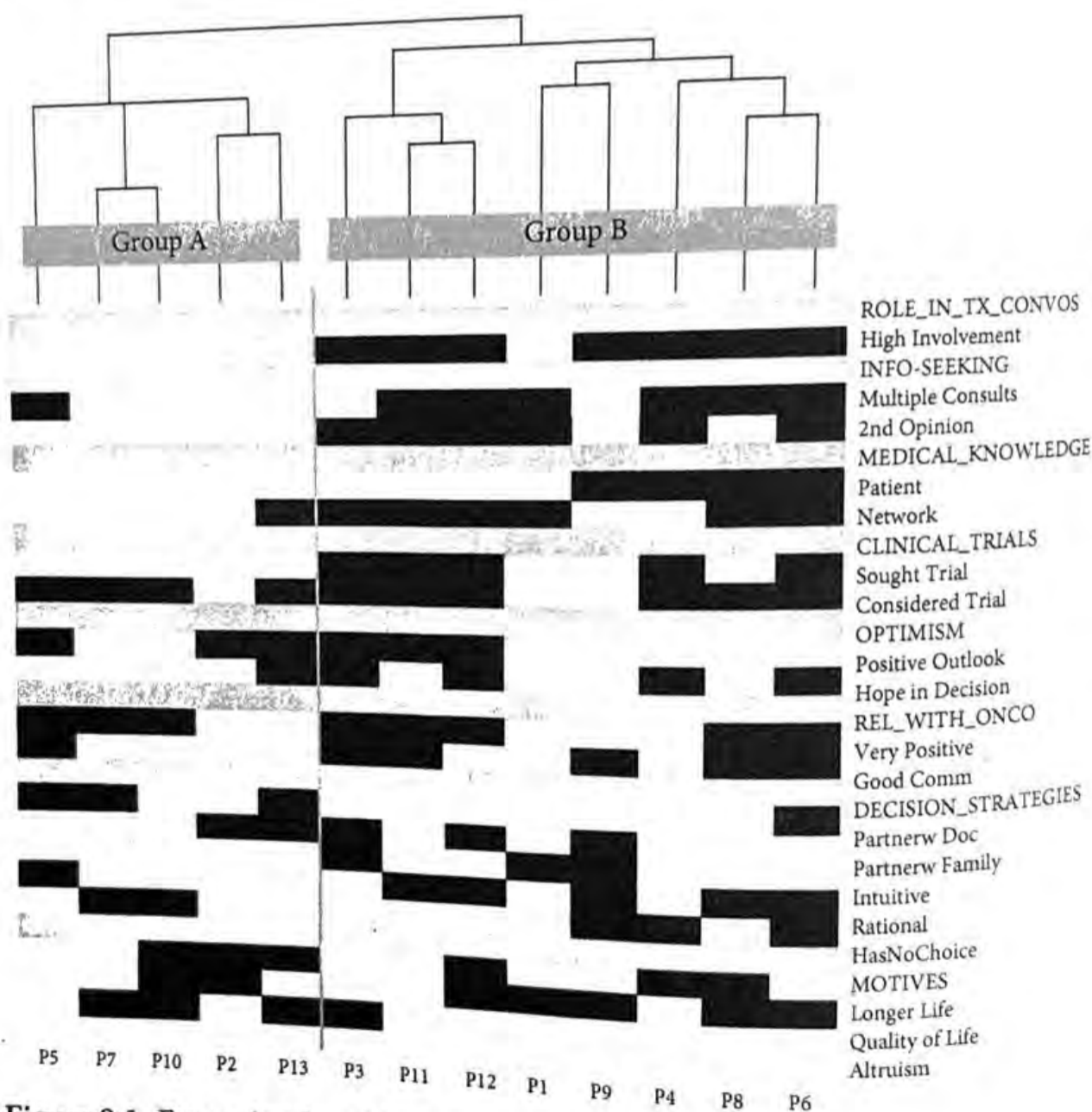


Figure 8.1 Example of an Ethnoarray

Columns represent individual patients. Rows represent the presence or absence of themes in patient data. Group A and Group B labels and a vertical grey line have been added for clarity.

A conventional thematic analysis of these data might highlight the importance of patients' involvement in treatment conversations and their information-seeking behaviors. Such an analysis might even note that these differences appeared to distinguish different types of patients, such as that most patients seemed to be highly involved in treatment conversations while a few patients were less so. But when all the cases can be examined and considered simultaneously, more systematic patterns become apparent. The two groups of patients are similar in many respects; few systematic differences separate the groups when it comes to their larger motives for seeking care, their decision-making strategies, and their relationship with their oncologists. Some patients in both groups approached their situation with optimism. The ethnoarray uses visual analysis to reveal patterns and systematicity in a broader range of ethnographic data than could be included in a conventional narrative analysis.

By displaying comprehensive data from an ethnographic study, the array can capture the entirety of an ethnographic project—findings that typically consume hundreds or thousands of pages of field notes and transcripts—in a summary fashion within a single image. This provides a window of transparency on ethnographic studies and encourages readers to dive more deeply into the data. In addition, however, the ethnoarray is consistent with two strategies for preserving ethnography's unique narrative richness.

One strategy is to provide readers with a broad overview of the entirety of the ethnographic dataset. Quantitative data analysts point out that thoughtfully constructed visual data displays are important not merely because they put an attractive face on one's data, but also because they provide opportunities for critical examination. Tukey, for example, highlights the potential for disastrous consequences when inelegant visual displays of data obscure important, actionable findings. The ethnoarray seeks to reveal variety and nuance in ethnographic data by encouraging readers to examine the narratives of each individual case within a dataset. Reading down the column of an ethnoarray captures the narrative dynamics of a single case. Conventional ethnography provides the opportunity for authors to richly describe the narrative histories of a limited number of cases. Typically these cases come from key informants. Some informants provide access to the field site and thus are the source of significant amounts of observational data while others may become key informants when they provide particularly rich interview data by drawing on their own powers of self-reflection and observation to articulate and interpret the social dynamics of the own

social setting. The narratives in conventional ethnography are, therefore, selected by the author as particularly rich examples of evidence or themes that the author values.

A vertical read of an ethnoarray provides a different type of narrative experience. Readers can examine any case they wish and examine how the evidence or themes they consider relevant are reflected in that case. They can select cases that may contrast with or even contradict the argument made by the author. They may discover counterfactual examples that shed new light on the author's claims, or they may gain new understanding of a subject's experience by reading down the ethnoarray column that captures the entirety of their case. Table 8.1 shows vertical narratives of two patients depicted in the ethnoarray. Comparing their narrative histories with the depiction of their case within the ethnoarray—as well as how their case compares to others both within and outside their group—provide the kind of narrative reassurance and immediacy that is a hallmark of ethnography.

A second strategy for capturing narrative richness is to provide readers with the ability to develop an emic appreciation of a subject's worldview, experiences, and locale. As envisioned (but not yet implemented), this richness could be provided to readers by linking coded raw data to each of the ethnoarray's visual cells. These data would provide a rich narrative sense of the data, and if combined with a vertical read of the ethnoarray could potentially provide unprecedented data transparency that allows readers to appreciate the experiences of many individuals or other cases in an ethnographic project—not just those of selected key informants.

The ethnoarray is thus an analytic approach to expand the breadth of ethnographic analysis and reportage while retaining the ability to explore narrative and empower readers to undertake interpretation. For the biomedical research community, this type of scaled ethnography presents itself as a familiar visual. It also challenges biomedical scientists—as well as social scientists—to acknowledge the tension that patterns of social life emerge from data reduction without erasing the narrative specificity and interpretive ambiguity that constitute all meaningful lives. Ethnography of greater breadth and scale has the potential to communicate this quality of social experience. In biomedicine, it can do so for an audience that already has the ability to code-switch between scientific rigor and clinical narrative. A tool that elegantly bridges rigor and narrative may ensure ethnographers a full seat at the table of biomedicine.

Table 8.1 Vertical Narratives

Reliant Outsider

Dennis (P7) is a white carpenter in his 50s who was referred to the cancer center after a lengthy diagnosis process. After learning he had melanoma, "there was only one option. It was go to SF and start treatment with [the oncologist]." He tells the interviewer that he does not know much about the different treatments available to him: "It's all mumbo jumbo to me... I'm not big into reading up on stuff like that." His caregiver wife, a cashier, keeps track of this information. In the course of this experience Dennis did not look for second opinions. He described his decision-making process as "always our decision, but I would always ask [the oncologist], you know, which way does he want to go. 'Cause I don't see how you ask a patient which direction you want to go, you know, when a doctor's been doing this for however many years. It makes no sense. So we pretty much just kind of let him—I mean, we agreed to everything that he wanted to do so we let, you know, pretty much followed his lead." He could not remember any point when he and his wife second-guessed a decision made that way. After a year of care at the cancer center he was told there were no remaining anti-cancer options for him unless he was willing to travel outside of California for trials, something he was not willing to do.

Active Insider

Gary (P12) is a white semiretired engineer in his 60s. When he was diagnosed he and his wife did not know anyone with melanoma, so they relied on research they did, their MD son's insights, and information and referrals they secured from doctors at three different institutions. Gary and his wife were proactive and effective in pushing for the care they wanted with the providers they wanted. Gary described his approach to decision-making as relatively "cautious": "We make sure we got the whole picture before we make a decision." He described weighing the pros and cons of different courses of action. Gary, his caregiver wife, and MD son used information they found via research and medical networking to make decisions together as a team. Throughout his care, Gary scrutinized oncologists' descriptions of the risks of different treatments, as his MD son had told him that oncologists tended to minimize the severity of treatment side effects. From early on Gary saw PD1 trials as the only potentially efficacious option available to him: "They've given me the distinct impression that this is a much better, although still experimental drug, both for minimizing side effects and chances of success... I want to get into [it] very badly and... as soon as possible... We have never wavered from that approach."

Integrating Mapping Technology with Ethnography to Expand the Scope of Data Collection

As ethnographers in the medical research and health sciences settings, we are particularly concerned with how to design research questions and collect, integrate, and represent different types and scales of data in ways that are relevant to the health sciences and clinical audiences. These concerns about research design and implementation are matched by our desire to maintain

the integrity and rigor of the ethnographic method, which has traditionally focused on in-depth fieldwork and rapport-building that enables a deep and nuanced understanding of social contexts and processes, as well as attention to how meaning is made (Messac et al. 2013). As such, from project development to implementation, our encounter with the medical research environment necessitates—and in fact, offers—new ways of thinking about how to ask and frame questions, how to integrate different methods to provide new insights into important problems where there have previously been roadblocks to progress, and, importantly, how to frame the work we do so that our research findings may lead to actionable interventions with implications for improving clinical practice or health policy.

Historically, anthropologists, whose primary method is ethnography, used many modes of data collection to try to gain a “holistic” view of a particular culture or aspect of society, including studying language, kinship structures, rituals, governance structures, and other aspects of everyday life (Evans-Pritchard 1976; Lévi-Strauss 1969; Benedict 2005; Mead 2001). This approach to fieldwork has been replaced with experiments with many different units of study, which constitutes a shift away from studying cultures as bounded entities. For example, anthropologists now explore assemblages of information through cases that are globally connected at many different scales (Ong and Collier 2005). Anthropologist Joao Biehl (2013) used an innovative approach by investigating one woman’s life story as a way to understand the politics of mental illness and social abandonment in Brazil. Jerry Zee (2017) follows pathways of dust storms across multiple sites from Inner Mongolia to Beijing to South Korea via communities of scientists, bureaucrats, and local citizens in order to understand relationships between historical, political, and environmental factors in anti-desertification effort in China. These are just a few examples among countless ethnographers who have worked with different scales and practices in order to change the scope and modes of data collection. This multiplicity of approaches is enabled by the inherent flexibility of the ethnographic approach to adapt to different research settings and morph to fit different types of encounters and research questions. There is a clear precedent for fostering connections with biomedical and health sciences to develop ethnographic approaches which themselves emerged from the research questions being asked and the particular context of the research being conducted (Cohen 2007 on bioavailability; Landecker 2007 and Solomon 2016 on metabolism; Haraway 1999 on immunity, and Mol 2002; Mol and Law 2004 on multiplicity and enactment). If what characterizes

ethnography is a deep sensitivity and interest in encounters, as both the setting for ethnographic work and all social life, then the questions that the health sciences push ethnographers to pose and the contexts of the studies we do in these settings enable new connections to emerge (Faier and Rofel 2014). Ethnography in this form has expanded from its earlier emphasis on a bounded research object—an ethnos—toward an experimental approach that reflects on itself and the object or problem on which it centers.

Much as Strathern (1988) argued for an expansion of the concepts we use through the encounter between the researcher and the field, in our work we are constantly drawn to the question of what ethnography looks like and how it changes in its encounter with biomedicine and the health sciences. This approach allows for new relations between ethnographers and scientists or medical personnel to emerge which have both collaborative and mutually productive potential. As part of this project, we also ask how we can be better enabled to translate our findings and approaches across disciplinary boundaries. In the case we discuss here, we examine how ethnography conducted within the biomedical setting led to new research questions. Furthermore, with the goal of identifying potential interventions, we were led to an approach that would allow us to collect and analyze data to help healthcare providers, community resource providers, and policymakers reach a better understanding of the social, emotional, and spatial dimensions of loneliness, social isolation, and burden among caregivers of people with Alzheimer's disease. We specifically attend to ways of expanding the modes of data collection and the scope of information or data that can be collected during a certain period of time. The scope of data, understood in this way, relates to the type and amount of data that can be collected, stored, and analyzed, as well as approaches to representation and visualization. Through these analytical approaches, new types of analyses and data representation are made possible.

Origins of Ethnographic Engagement with Mapping: Addressing Caregiver Burden in Alzheimer's Disease

The imperative to incorporate multiple scales and modes of inquiry within an ethnographic study emerged in this case from an identified problem in our research among caregivers of people with Alzheimer's disease and

related dementias. As a medical anthropologist in a clinical setting, I (AB) am embedded within a team of researchers in a memory clinic within a Department of Neurology implementing a clinical trial, the Care Ecosystem, focused on implementing care navigation for people with dementia and their caregivers. The Care Ecosystem is a telephone- and web-based supportive care intervention for people with dementia and their caregivers based at the University of California, San Francisco and the University of Nebraska Medical Center. One major focus of the study was to support caregivers and improve caregiver quality of life. I was tasked with gaining a qualitative understanding of the experiences of caregivers, both in their everyday life and through their interaction with the care navigators, in order to complement the quantitative and survey measures being collected and analyzed as part of the study.

More than 15 million family members or friends provide care for individuals with Alzheimer's disease or other dementias in the United States, which involves immense emotional, physical, and practical support. Social isolation impacts as many as 17% of all older adults in the United States (65+), and loneliness is experienced by as many as 40% of these older (Theeke 2010; Hawkey and Cacioppo 2010). Due to additional burdens of caregiving, caregivers of people with Alzheimer's disease are at an even higher risk for these negative health outcomes. Social isolation and loneliness contribute to caregiver burden, depression, and disease, conveying a higher risk for dementia, cardiovascular disease, inability to continue caregiving, and early death (Luo et al. 2012; Jennings et al. 2015; Valtorta et al. 2016). To date, efforts to support caregivers have focused heavily on skills acquisition, education, counseling, and respite (National Academies of Sciences 2016). Yet studies show only a quarter of caregivers access these services. Despite these numbers, the same types of services continue to be implemented, even though many caregivers are not making use of them.

With this context in mind, I began my ethnographic research for the project. In Nebraska I conducted interviews and participant observation with fifteen family caregivers of people with dementia, as well as care team navigators and clinical team members. I sought to understand experiences of everyday life as a caregiver through my interview questions, and by meeting people in their homes and participating in their daily activities. I asked participants to describe what life is like as a caregiver, what happens on good days and what happens on difficult days, as well as to share the emotions involved in these experiences and to tell me about their social networks and

the community resources they use. Simultaneously, the Care Ecosystem study collects quantitative data about these caregivers at six-month intervals. Measures include caregiver burden, quality of life scores, depression scores, and other quantitative data. The richness and depth I was able to see into the lives of the caregivers was strengthened by spending time in their homes where, with some caregivers, I was able to use a traditional participant observation approach to engage in their day-to-day activities with them. Through my visits in vastly different settings in both urban and rural Nebraska, I felt the need to get both a deeper and broader understanding of caregivers' day-to-day social and emotional experiences, how they spend their time, their use of resources, and how their surroundings, both in the home and in the community, shaped their experiences.

In particular, a common refrain I heard was, "My world keeps getting smaller." From my interviews, I knew this description depicted the social, spatial, and temporal experiences of being a caregiver: not being able to leave the home as often, less time to engage in activities, less social connections as people dropped away. Following are examples from my fieldnotes and an interview with two a caregiver that represent a more traditional approach to ethnographic fieldwork.

I visited Mr. and Mrs. J. in their one-bedroom apartment in a low-income housing development in urban Omaha. The apartment is dark, cramped, and messy with medications scattered all over the table in a jumble. Mr. J (who has advanced Alzheimer's disease) sits in a giant easy chair in the back room, his coloring book sprawled on a table and his intricate drawings on the wall. Mrs. J, his wife and caregiver, discovered that while he has limited ability to communicate or remember anymore, he finds great joy in coloring. Year-round Halloween decorations adorn the walls because they make him happy, it's his favorite holiday. Mrs. J sequesters him to the back room because sometimes, she said, he gets violent. She sleeps in the front room on the couch with her cat. They communicate through the language of "coffee." When he needs something, anything, she told me, he says "coffee." She spends most of her time with the cat while he is sleeping or agitated. She feels very isolated. She told me she only gets out of the house twice a week to take a taxi to Walmart to grocery shop. She explains that Walmart is where she socializes. She otherwise sees herself as extremely independent, but still cries when discussing her loneliness, telling me, "*The hardest thing dealing with this is the solitude.*"

Following is an excerpt from our interview:

INTERVIEWER: So you were saying you do some walking now, so you've been able to extend your walks?

CAREGIVER: Yes.

INTERVIEWER: That's great.

CAREGIVER: And when I go to Walmart, I talk to everybody, so they're all kind of, oh there's the crazy lady! (Laughs). And when I have the cart I'm more mobile, i can walk better, so it's almost like having a walker. It usually takes me about a half hour or forty-five minutes at Walmart.

INTERVIEWER: How do you get there?

CAREGIVER: Cab.

INTERVIEWER: How often do you usually do that?

CAREGIVER: Usually about twice a week.

INTERVIEWER: That's nice, so it's a little outing.

CAREGIVER: Yes, it is, I feel like I escape.

INTERVIEWER: Have you ever thought about doing a support group or a meeting or anything like that?

CAREGIVER: No, because it's hard for me to get out. There are times when I can tell him I'm leaving, but see how his hand is twitching, he will get so his whole body is doing that, and I get nervous, so I don't like to leave him alone, so I can't just pick up and go when I want. There are windows when I can get away.

INTERVIEWER: What's your fear?

CAREGIVER: That he would try to get out or something would happen, he would get up and he would fall, or he would be hurt while I was gone. And, the guilt would not be happy. Caretaker, babysitter, a pain in the ass. I'm sure he has several different names for me.

The preceding description fits a more traditional ethnographic approach to both fieldwork and the representation of data: a description of participant observation with a narrative that illustrates a single person's experiences. Through this early fieldwork it became clear that we do not fully understand how to intervene in caregivers' social and physical experiences in the home and community environments to reduce the social isolation and loneliness so commonly experienced. One of the limitations of ethnographic research in a medical setting is the ability to spend the same kind of time we might spend during more traditional fieldwork. Another is that there are many elements

of the person's environment, physical, social, and structural, that might have implications for the problem I was looking at, including what services people access, when, and how that were out of the purview of the time I spent with the family. While I was able to spend a brief amount of time with people in their day-to-day lives, I wanted to expand the scope of the data I was using to address this common problem. What were their neighborhood or community characteristics? How much time did they spend in different rooms in their homes or accessing different services in the community? Who did they interact with? Where did these interactions happen? How did they get there? What happened when I was not around?

Furthermore, while the case description and thematic analysis approach is useful for representing some of the richness ethnographers experience during fieldwork, it did not always seem a satisfying approach to represent the issues I encountered in a way that could be useful to clinical or policy audiences. I wanted to be able to illustrate core dynamics involved, both for individual caregiver-patient dyads as well as for making comparisons across caregivers, locations, or other points of interest. I thus questioned what strategies could be used to make the data speak to clinicians, policymakers, and scientists, while still being legible to other social scientists. As such, I sought an approach that would allow me greater insight into people's activity, movement, social networks, and emotional experiences that were connected to the ways they moved about in space and where they spent their time, and could be represented computationally. Furthermore, I hoped that such an approach would allow for case comparisons using different types of data and units of comparison.

As I moved into thinking about new iterations to my approach, I became captivated by both the emotional experiences of social isolation and loneliness, as well as the spatial and temporal and geographical dimensions and implications, with the goal of eventually developing interventions that would actually be located at sites where caregivers spend the most time. Both anthropologists and geographers examined how people understand, use, and make social and political meaning through space and in time (Gupta and Ferguson 1997; Caldeira 2000; Marcus 1995; Caquard 2013; Buliung and Kanaroglou 2006; Kwan 2008; Malkki 1992). Similarly, I wanted to understand aspects of space and time in regards to where people went during the day—both in their homes and in their communities, how long they spent in different places and why, who they talked to, what feelings or experiences they had in different locations and spaces, how neighborhoods, transportation,

and resource environment impacted their experiences, and ways to think about comparing across caregivers that did not make assumptions about the salience of pre-given categories such as "rural" and "urban," or take for granted what counts as a social connection. These questions, I felt, would help me to answer the more applied question: How could we find new ways to identify caregivers at risk for social isolation and loneliness, and intervene in ways that people would actually find meaningful and adaptable to their current experiences and environments?

As a member of the Care Ecosystem research team, I was engaged with the questions that were most concerning to clinicians. I was also inspired by another colleague's work. As a geriatrician and an engineer, he had developed a functional monitoring component for the Care Ecosystem study. The idea was to provide smart watches and smart sensors to the person with dementia in order to track his or her physical activity and movement. Implications from this work include the possibility of creating falls-prediction modeling based on patient movement in the months leading up to a major fall or health emergency (Zylstra et al. 2018). To expand the scope of data collection and the possibility for this type of modeling that could be relevant to applied audiences, I wanted to collect a lot more data in a short period of time through a number of different instruments and computational techniques (specifically, monitoring, observations, interviews, and public data sets). I felt that engaging in multiple modes of data collection could increase both the depth and breadth of data in order to create new assemblages of information that could lead to more possibilities for insightful comparative analysis. My encounter as part of a clinical research team led to another cross-disciplinary interaction, as I formed a collaboration with a geographer in order to gain insights into how ethnographic data in the traditional sense might be incorporated into technological and visual systems both as a mechanism to study experiences, but also for representational purposes.

An ethnographic approach that uses geographic information systems (GIS) technology, interviews, and observations can be used to map and describe caregivers' experiences of social connection and isolation in relationship to their activity within the home and community at multiple different scales (Kwan and Ding 2008; Fielding 2009; Shaw, Yu, and Bombom 2008; Jung and Elwood 2010; Buliung and Kanaroglou 2006). This approach allows for mixed-method data collection that incorporates GPS tracking, activity data, a social dimensions surveys, and publicly available data with ethnographic interviews and participant observation (Table 8.2). Data about

Table 8.2 Types of Data for Use in Mapping

	Measurement
Caregiver Tracking	
Location and time	GPS data: geographic location and duration
Social dimension survey	Survey of social contacts
Activity data	Qualitative findings
Community Environment	Measurement
Home/residence	Point on maps, layout of home
Location of medical centers, hospitals, public clinics	Points on maps, counts of sites in neighborhoods
Location of caregiver support sites	Points on maps, counts of sites in neighborhoods
Location of AD-related services and organizations	Points on maps, counts of sites in neighborhoods
Community social events, classes, supports	Points on maps, counts of sites in neighborhoods
Location of transportation routes	Lines on maps, counts of routes in neighborhoods
Location of pharmacies	Points on maps, counts of sites in neighborhoods
Location of grocery stores	Points on maps, counts of sites in neighborhoods
Location and type of housing	Points on maps, counts of sites in neighborhoods
Location of "other" as defined by caregivers in interviews	Points on maps, counts of sites in neighborhoods
Socioecological Characteristics	Measurement
Median household income	Median income of all household members in 2009
Concentrated poverty	% of households under the poverty line
Racial heterogeneity	% of African Americans, % Whites, % Asians, % non-White Hispanics
Racial isolation	% of one racial group/all others
Walkability score (Moudon and Lee n.d.)	The number of typical consumer destinations within walking distance of a house, with scores ranging from 0 (car dependent) to 100 (walkable)
Social and Emotional Characteristics	Measurement
Social and emotional experiences	Qualitative findings
Survey results	Survey findings

locations, time spent, and experiences is analyzed both through qualitative software (e.g., ATLAS.Ti), and through ArcGIS, a software used to map and analyze geospatial activity. In this approach, caregivers wear GPS trackers to continuously monitor geolocation. The output reveals activity space, locations, and duration, which give an accurate and objective read of people's movement in space and the time they spend at different places. Caregivers

also complete a social dimensions survey, which provides insights into their social interactions. In this survey they describe the social relationship with each contact, including 1) frequency of typical contact; 2) emotional support from contact; and 3) service provided. During ethnographic interviews, caregivers reflect on social and emotional experiences at different locations that are identified through the GPS data collected prior to interviews. Interview responses can be integrated with the mapping data, which also includes publicly available data related to census, transportation, walkability, health services, and AD resources.

All of this data is brought together in a mixed-methods geo-database that can be linked to coding and qualitative analysis in ATLAS.ti, with community environment and socioecological characteristics stored as layers, and integrated with ethnographic findings, which provide more depth and nuance. Maps produced based on these layers can help researchers to visualize and analyze caregivers' physical activity space in their home and community environments, the time spent at different locations, and how physical activity space and time intersects with qualitative social and emotional experience. Some aspects of caregiver experience that can be analyzed using this approach include: movement, activities, time, duration, social contacts, and social emotional experience. For example, we can evaluate the quality of the home and community environment for the social needs of a caregiver (e.g., resources available, proximity of activities and contacts, time spent), and assess their role in a caregiver's activity space. We can visually represent and analyze the intersection of caregivers' physical and social experiences by analyzing the maps and ethnographic data together, and integrating the ethnographic data into the maps. The computational program, ArcGIS can be used to create map layers to integrate social and emotional characteristics from interviews, observations, and surveys with the physical activity space maps to examine the interactions of social experience and space and time dimensions. Based on inputs we will create maps and analyze relationships between movement, resources, time spent in particular salient places, and caregiver experiences.

One example of a mapping method used in GIS is called space-time paths. Space-time paths allow for the mapping and identification of contextual influences and how they vary across space and time, using GIS and detailed GPS data (Kwan 2012; Lee and Kwan 2011). This approach allows for the representation of a trajectory in 3D space in ArcGIS as a way to visualize the caregiver's movement in space and time in combination with social and

emotional experiences (Figure 8.2). The vertical axis shows temporal progression, and the horizontal axis shows geographical movement of the caregiver's activity space (Richardson et al. 2013). Space-time paths enable assessment of how aspects of the social or built environment integrate with spatial and temporal movement. Maps show caregivers' activities, including use of resources, social interactions, and emotional experiences, and how these unfold across space and over time. These maps can help in assessments of social and emotional dimensions related to individual and aggregated caregivers' movement through their physical activity space. Ethnographic data provides insights into thoughts, decisions, social networks, context, emotions, and experiences. We aim to use these maps to enable complex comparisons of results across caregivers based on different parameters or characteristics such as where they live, caregiver burden score, or other factors.

Overall, this approach allows for new ways of expanding the scope of data collected and the kinds of comparisons that are possible while also maintaining the depth and nuance of traditional ethnography through in-depth interviews and participant observation with caregivers. We are able to

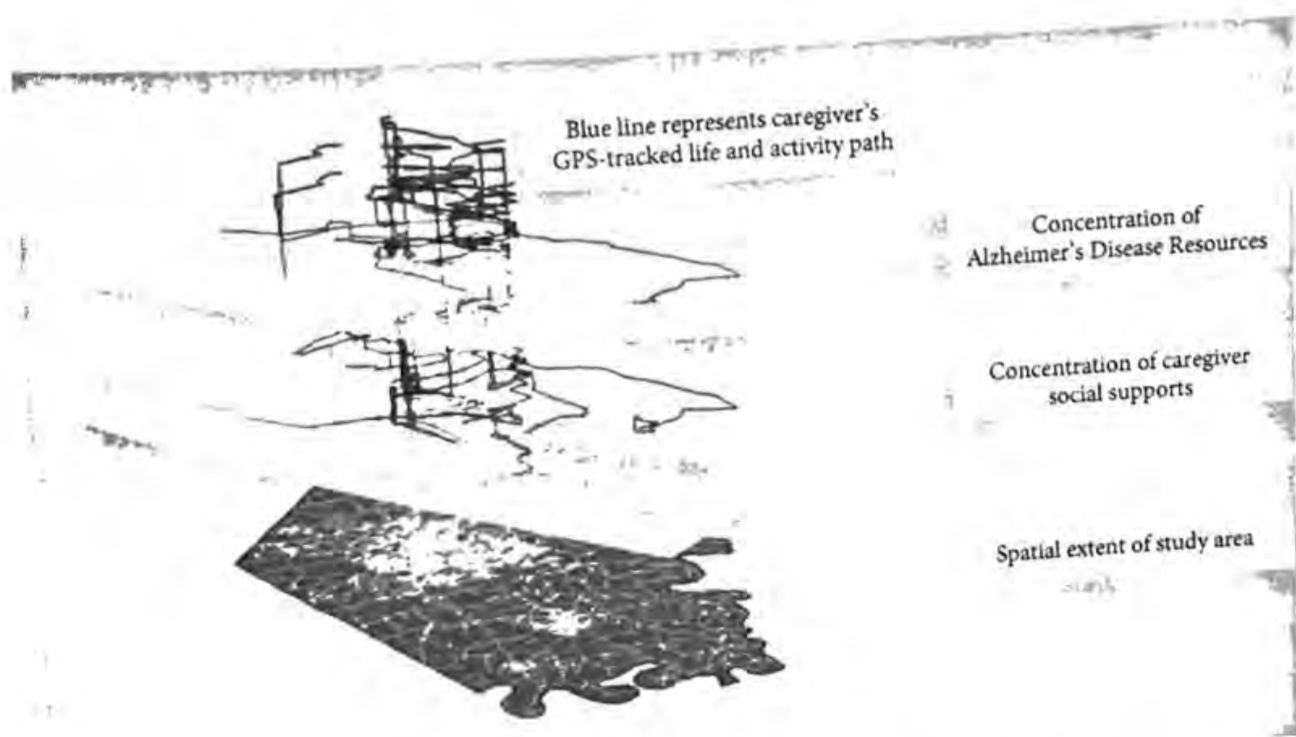


Figure 8.2 Example of Caregiver Space-Time Path Map Using ArcGIS Software
 Life paths of caregivers provide assessments of their social and environmental contexts and contacts and how they are related to movement. Caregiver life paths are shown as trajectories that unfold along the vertical axis, which represent time; the bottom horizontal plane represents the spatial extent of the study area. Above this are two horizontal planes that illustrate the spatial distribution of social and resource factors shaping caregiver experience. Dark line represents caregiver's GPS-tracked life and activity path. Adapted from Richardson et al. (2013).

think about new ways to understand dynamics that clearly have intersecting spatial, temporal, and social elements at play, and are connected to resource environments, activity space, and social and emotional experience. This computer-assisted approach to fieldwork offers an expanded scope of data, where more data is collected and the amount of useful information at a given period of time is higher, allowing for more depth and nuance of understanding of a caregiver's experiences.

Applied Implications and Future Directions

While this approach is still in development, there are many potential implications for the method that can be used to help develop applied interventions in both community and clinical settings. In what follows, I discuss three potential areas of forward movement.

Integrating interviews, observations, and GIS data can provide insights into where to locate and how to adapt caregiver interventions that have been shown to be efficacious in addressing caregiver burden so that they are more accessible to caregivers. For example, once we identify the locations where caregivers spend time that provide the most supportive interactions, we might be able to adapt evidence-based interventions so they can be embedded in community settings, such as chain stores, local merchants, or places of worship, and delivered in the course of such routine activities as grocery shopping. To develop this intervention, we would consider how to adapt existing evidence-based interventions to be successful in new community locations and how to engage local merchants as stakeholders. There is a precedent for relocating interventions to novel care delivery settings where meaningful social interactions occur. In a randomized controlled trial study to reduce blood pressure in black men, a pharmacist-assisted hypertension management program was most successful when integrated into a barber-shop setting.

GIS information can provide local clinicians with insights about which caregivers are most at risk for loneliness and social isolation. For many providers, it is often difficult to identify when more support is needed and for whom. My previous research on strategies to integrate dementia care into primary care highlights the need for designing an intervention that will be accessible to clinical teams and compatible with their busy clinic schedules.

Thus, intervention development will focus on how to effectively integrate GIS data with the electronic health record (e.g., using a smartphone or other activity tracker data) to inform a primary prevention intervention. Sharing GIS data with providers, including physicians, social workers, and nurses, can help them identify whether someone is especially isolated compared to individual, neighborhood, and community-level normative characteristics. Ethnographic and GIS analysis can help identify areas where caregivers encounter government and policy programs that are outside of the healthcare system, and where investment in novel support programs might be most effective. A long-term goal is to engage community resource providers and city policymakers in developing resources to help caregivers better connect to support. For example, in the United Kingdom, postal carriers were identified as a nontraditional means for intervening to provide support for older adults who were isolated at home. These postal workers helped connect older adults with community resources. By knowing where caregivers spend their time (GIS) and with whom they interact (ethnography) we will identify targets for novel caregiver support interventions that reduce artificial boundaries between sectors and may inform policy.

Overall, expanding the scope and type of data collected can help to identify assets and resilience in caregivers who remain connected with social networks, mechanisms involved in those who are especially burdened, and identify interventions into loneliness and social isolation that exist at the intersection of space, place, time, and sociality. Integrating social and spatial information into studies of caregiving, can offer health and community resource providers a better understanding of the mechanisms of social isolation, loneliness, and connection that contribute to caregiver burden or well-being. Expanding the scope of ethnographic research through the integration of geographic-based computational techniques offers the potential to enhance health and resource providers' interactions with caregivers in places and at times that are most relevant, as well as to tailor services provided outside of healthcare settings. Furthermore, GIS allows for anticipatory modeling, for example, by using inputs from multiple sites and cases to eventually create a model that can simulate behavior or simulate the impact of interventions. While GIS is one example of how this can be done, integrating other types of passive monitoring with ethnographic analysis can help ethnographers understand links between structural features of the environment and people's actual practices.

Discussion

In this chapter we highlight the value of ethnography for studies in medicine and suggest ways that social scientists can advance ethnographic inquiry by engaging with models of science beyond their disciplinary orthodoxies. Ethnography is a diverse and contested field of practice, and the computational innovations we describe build on traditions that have been used in the social sciences for decades. These innovations have diffused poorly to ethnography, however, and some view them as antithetical to the ethnographic tradition. We conceive of ethnography broadly and suggest that these innovations are commensurate with the ethnographic project both methodologically and theoretically. Methodologically, we focus on providing robust interpretative analysis of the meaningful behaviors and cultural practices of groups, movements, organizations, or institutions. Theoretically, our ethnographic work is epistemologically consistent with sociological research on the causes and consequences of social action—even as we recognize that ethnography's mandate extends more readily to elucidating potential mechanisms of action than to drawing conclusions about cause and effect.

Our techniques and the origin stories behind them differ, but both respond to needs we experienced in our work in the applied biomedical research environment. The techniques and innovations we describe typically require specific types of data collection and analysis practices. Both approaches build on the textual data recorded in field notes derived from participant observation of research subjects in naturalistic settings. Other types of ethnographic data, including in-depth interviews with research subjects or key informants, text data, or visual data, can also be incorporated in this approach. Analytically, ethnography includes a range of approaches along the deductive/inductive spectrum. These innovations assume the ethnographer enters the field with some a priori analytical foci or priorities; purely exploratory, inductive studies, such as studies that truly start with the grounded theory question of "what is going on here" are unlikely to benefit from the types of innovations we describe. Consistent with the deductive approach, analysts who seek to use these innovations will typically be comfortable conducting thematic analysis of ethnographic data. Both innovations require computer-assisted qualitative data analysis.

This chapter examines the potential for ethnographers and ethnographic studies to be shaped in encounters with other disciplines, and specifically

to inform the practice of biomedicine. The rich ethnographic literature on medicine has often adopted a critical perspective on medical practice or used medicine as a case study for studies of more general social principles or dynamics. Our focus is more practical and applied: How can ethnography inform and improve healing practices across a range of settings from the clinic to the community to policy? Medicine's longstanding appreciation for narrative and culture make it a potentially fertile ground for ethnographic contribution. The profession's focus on quantification leads us to consider how larger-scale comparative ethnographic projects—including projects that use novel approaches for representing and interpreting ethnographic findings—may advance the practice of medicine and the health of populations. In comparative studies in particular, ethnographers seek to examine how phenomenon or behavioral practice varies across and among distinct contexts including practice settings, patient populations, clinical conditions, or treatment modalities.

References

- Abramson, Corey M., and Daniel Dohan. 2015. "Beyond Text: Using Arrays to Represent and Analyze Ethnographic Data." *Sociological Methodology* 45, no. 1 (August): 272–319.
- Abramson, Corey M., Jacqueline Joslyn, Katherine A. Rendle, Sarah B. Garrett, and Daniel Dohan. 2018. "The Promises of Computational Ethnography: Improving Transparency, Replicability, and Validity for Realist Approaches to Ethnographic Analysis." *Ethnography* 19, no. 2: 254–284.
- Becker, Howard S. 2009. "How to Find Out How to Do Qualitative Research." *International Journal of Communication* 3: 9.
- Benedict, Ruth. 2005. *Patterns of Culture*. Boston: Houghton Mifflin.
- Benedict, Ruth, and Ian Buruma. 2006. *The Chrysanthemum and the Sword: Patterns of Japanese Culture*. New York: Mariner Books.
- Biehl, João. 2013. *Vita: Life in a Zone of Social Abandonment*. Berkeley: University of California Press.
- Bosk, Charles. 1979. *Forgive and Remember: Managing Medical Failure*. Chicago: University of Chicago Press.
- Buliung, Ronald N., and Pavlos S. Kanaroglou. 2006. "A GIS Toolkit for Exploring Geographies of Household Activity/Travel Behavior." *Journal of Transport Geography* 14, no. 1: 35–51.
- Caldeira, Teresa Pires do Rio. 2000. *City of Walls: Crime, Segregation, and Citizenship in São Paulo*. Berkeley: University of California Press.
- Caquard, Sébastien. 2013. "Cartography I: Mapping Narrative Cartography." *Progress in Human Geography* 37, no. 1: 135–144.
- Charmaz, Kathy. 1995. "Grounded Theory." In *Rethinking Methods in Psychology*, edited by Jonathan A. Smith, Rom Harré, and Luk Van Langenhove, 27–49. London: SAGE Publications.

- Cohen, Lawrence. 2007. "Operability, Bioavailability, and Exception." In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, edited by A. Ong and S. Collier, 79–90. Oxford: Blackwell.
- Creswell, John W. 2007. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*, 2nd ed. Thousand Oaks, CA: SAGE Publications.
- Desmond, Matthew. 2019. "Eviction Lab." <https://evictionlab.org>.
- Devers, K. J. 1999. "How Will We Know 'Good' Qualitative Research When We See It? Beginning the Dialogue in Health Services Research." *Health Services Research* 34, no. 5, Pt. 2 (December): 1153–1188.
- Devers, Kelly J. 2011. "Qualitative Methods in Health Services and Management Research: Pockets of Excellence and Progress, but Still a Long Way to Go." *Medical Care Research and Review* 68, no. 1 (February 20): 41–48.
- Dunn, Laura B., Jim Wiley, Sarah Garrett, Fay Hlubocky, Christopher Daugherty, Laura Trupin, Pamela Munster, and Daniel Dohan. 2016. "Interest in Initiating an Early Phase Clinical Trial: Results of a Longitudinal Study of Advanced Cancer Patients." *Psycho-Oncology* 26, no. 10: 1604–1610.
- Evans-Pritchard, E. E. 1976. *Witchcraft, Oracles, and Magic among the Azande*. Oxford: Clarendon Press.
- Faier, Lieba, and Lisa Rofel. 2014. "Ethnographies of Encounter." *Annual Review of Anthropology* 43, no. 1 (October 21): 363–377.
- Fielding, Nigel, and César A. 2009. "CAQDAS-GIS Convergence: Toward a New Integrated Mixed Method Research Practice?" *Journal of Mixed Methods Research* 3, no. 4 (October): 349–370.
- Fisher, Jill A., Marci D. Cottingham, and Corey A. Kalbaugh. 2015. "Peering Into the Pharmaceutical 'Pipeline': Investigational Drugs, Clinical Trials, and Industry Priorities." *Social Science & Medicine* 131 (April): 322–330.
- Fisher, Jill A., and Corey A. Kalbaugh. 2011. "Challenging Assumptions about Minority Participation in US Clinical Research." *American Journal of Public Health* 101, no. 12 (December): 2217–2222.
- Garrett, Sarah B., Corey M. Abramson, Katharine A. Rendle, and Daniel Dohan. 2018. "Approaches to Decision-Making among Late-Stage Melanoma Patients: A Multifactorial Investigation." *Supportive Care in Cancer* 27, no. 3 (August): 1059–1070.
- Garrett, Sarah B., Christopher J. Koenig, Laura Trupin, Fay J. Hlubocky, Christopher K. Daugherty, Anne Reinert, Pamela Munster, and Daniel Dohan. 2017. "What Advanced Cancer Patients with Limited Treatment Options Know about Clinical Research: A Qualitative Study." *Supportive Care in Cancer* 25, 10 (October): 3235–3242.
- Glaser, Barney G., and Anselm L. Strauss. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine Publishing Company.
- Greenhalgh, Trisha, Ellen Annandale, Richard Ashcroft, James Barlow, Nick Black, Alan Bleakley, et al. 2016. "An Open Letter to The BMJ Editors on Qualitative Research." *BMJ* (February): i563.
- Gupta, Akhil, and James Ferguson. 1997. *Culture, Power, Place: Explorations in Critical Anthropology*. Durham, NC: Duke University Press.
- Haraway, Donna. 1999. "The Biopolitics of Postmodern Bodies: Determinations of Self in Immune System Discourse." In *Feminist Theory and the Body: A Reader*, edited by J. Price and M. Shildrick, vol. 1, no. 1, 203. New York: Routledge.
- Hawley, Louise C., and John T. Cacioppo. 2010. "Loneliness Matters: A Theoretical and Empirical Review of Consequences and Mechanisms." *Annals of Behavioral Medicine* 40, no. 2 (October 22): 218–227.

- Jennings, Lee A., David B. Reuben, Leslie Chang Evertson, Katherine S. Serrano, Linda Ercoli, Joshua Grill, Joshua Chodosh, Zaldy Tan, and Neil S. Wenger. 2015. "Unmet Needs of Caregivers of Individuals Referred to a Dementia Care Program." *Journal of the American Geriatrics Society* 63, no. 2 (February 1): 282-289.
- Jung, Jin Kyu, and Sarah Elwood. 2010. "Extending the Qualitative Capabilities of GIS: Computer-Aided Qualitative GIS." *Transactions in GIS* 14, no. 1: 63-87.
- Katz, Jack. 1997. "Ethnography's Warrants." *Sociological Methods & Research* 25, no. 4: 391-423.
- Kleinman, Arthur. 1978. "Concepts and a Model for the Comparison of Medical Systems as Cultural Systems." *Social Science & Medicine* 12: 85-93.
- Koenig, Christopher J., Evelyn Y. Ho, Laura Trupin, and Daniel Dohan. 2015. "An Exploratory Typology of Provider Responses That Encourage and Discourage Conversation about Complementary and Integrative Medicine during Routine Oncology Visits." *Patient Education and Counseling* 98, no. 7 (July): 857-863.
- Kuper, A., S. Reeves, W. Levinson. 2008. "An Introduction to Reading and Appraising Qualitative Research." *Bmj.Com*, May, 2019. <https://www.bmj.com/content/337/bmj.a288.full.pdf+html>.
- Kwan, Mei Po. 2008. "From Oral Histories to Visual Narratives: Re-Presenting the Post-September 11 Experiences of the Muslim Women in the USA." *Social and Cultural Geography* 9, no. 6: 653-669.
- Kwan, Mei-Po. 2012. "How GIS Can Help Address the Uncertain Geographic Context Problem in Social Science Research." *Annals of GIS* 18, no. 4: 245-255.
- Kwan, Mei-Po, and Guoxiang Ding. 2008. "Geo-Narrative: Extending Geographic Information Systems for Narrative Analysis in Qualitative and Mixed-Method Research." *The Professional Geographer* 60, no. 4 (September 16): 443-465.
- Lamont, Michèle, and Patricia White. 2008. Workshop on Interdisciplinary Standards for Systematic Qualitative Research. National Science Foundation. Washington, DC: National Science Foundation.
- Landecker, Hannah. 2007. *Culturing Life: How Cells Became Technologies*. Cambridge, MA: Harvard University Press.
- Lee, Jae Yong, and Mei-Po Kwan. 2011. "Visualisation of Socio-Spatial isolation Based on Human Activity Patterns and Social networks in Space-Time." *Tijdschrift Voor Economische En Sociale Geografie* 102, no. 4: 468-485.
- Lévi-Strauss, Claude, John Richard Von Sturmer, James Harle Bell, and Rodney Needham. 1969. *The Elementary Structures of Kinship*. Boston: Beacon Press.
- Lock, Margaret M. 2002. *Twice Dead: Organ Transplants and the Reinvention of Death*. Berkeley: University of California Press.
- Luo, Ye, Louise C. Hawkley, Linda J. Waite, and John T. Cacioppo. 2012. "Loneliness, Health, and Mortality in Old Age: A National Longitudinal Study." *Social Science & Medicine* 74, no. 6: 907-914.
- Malkki, Liisa. 1992. "National Geographic: The Rooting of Peoples and the Territorialization of National Identity Among Scholars and Refugees." *Cultural Anthropology* 7, no. 1 (February): 24-44.
- Marcus, George E. 1995. "Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography." *Annual Review of Anthropology* 24, no. 1 (October): 95-117.
- Maurer, Bill. 2005. *Mutual Life, Limited: Islamic Banking, Alternative Currencies, Lateral Reason*. Princeton, NJ: Princeton University Press.
- Mead, Margaret. 2001. *Coming of Age in Samoa: A Psychological Study of Primitive Youth for Western Civilisation*. 1928. Reprint, New York: Perennial Classics.

- Messac, Luke, Dan Ciccarone, Jeffrey Draine, and Philippe Bourgois. 2013. "The Good-Enough Science-and-Politics of Anthropological Collaboration with Evidence-Based Clinical Research: Four Ethnographic Case Studies." *Social Science and Medicine* 99: 176-186.
- Miles, Matthew B., and A. Michael Huberman. 1994. *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks, CA: SAGE Publications.
- Mol, Annemarie. 2002. *The Body Multiple: Ontology in Medical Practice*. Durham, NC: Duke University Press.
- Mol, Annemarie, and John Law. 2004. "Embodied Action, Enacted Bodies: The Example of Hypoglycaemia." *Body & Society* 10, no. 2-3 (June): 43-62.
- Moudon, Anne Vernez, and Chanam Lee. 2018. "Walking and Bicycling: An Evaluation of Environmental Audit Instruments." *American Journal of Health Promotion* 18, no. 1: 21-37.
- National Academies of Sciences, Engineering, and Medicine. 2016. *Families Caring for an Aging America*. Edited by R. Schulz and J. Eden. Washington, DC: National Academies Press.
- O'Brien, Bridget C., Ilene B. Harris, Thomas J. Beckman, Darcy A. Reed, and David A. Cook. 2014. "Standards for Reporting Qualitative Research: A Synthesis of Recommendations." *Academic Medicine: Journal of the Association of American Medical Colleges* 89, no. 9 (September): 1245-1251.
- Ong, Aihwa., Stephen J. Collier, and Wiley InterScience. 2005. *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. Oxford: Blackwell.
- Petryna, Adriana. 2009. *When Experiments Travel: Clinical Trials and the Global Search for Human Subjects*. Princeton, NJ: Princeton University Press.
- Ragin, C. C., and H. S. Becker. 1992. *What Is a Case?: Exploring the Foundations of Social Inquiry*. Cambridge: Cambridge University Press.
- Ragin, Charles C., Joane Nagel, Patricia White, and National Science Foundation Sociology Program. 2004. Workshop on Scientific Foundations of Qualitative Research. National Science Foundation, Washington, DC: National Science Foundation.
- Reeves, Scott, Ayelet Kuper, and Brian David Hodges. 2008. "Qualitative Research Methodologies: Ethnography." *BMJ (Clinical Research Ed)* 337 (August): a1020-a1020.
- Richardson, D. B., N. D. Volkow, M.-P. Kwan, R. M. Kaplan, M. F. Goodchild, and R. T. Croyle. 2013. "Spatial Turn in Health Research." *Science* 339, no. 6126 (March): 1390-1392.
- Shaw, Shih Lung, Hongbo Yu, and Leonard S. Bombom. 2008. "A Space-Time GIS Approach to Exploring Large Individual-Based Spatiotemporal Datasets." *Transactions in GIS* 12, no. 4: 425-441.
- Small, M. L. 2009. "How Many Cases Do I Need?: On Science and the Logic of Case Selection in Field-Based Research." *Ethnography* 10, no. 1 (March): 5-38.
- Solomon, Harris. 2016. *Metabolic Living: Food, Fat and the Absorption of Illness in India*. Durham, NC: Duke University Press.
- Stokols, Daniel. 2006. "Toward a Science of Transdisciplinary Action Research." *American Journal of Community Psychology* 38, no. 1-2 (September): 79-93.
- Stokols, Daniel, Shalini Misra, Richard P. Moser, Kara L. Hall, and Brandie K. Taylor. 2008. "The Ecology of Team Science: Understanding Contextual Influences on Transdisciplinary Collaboration." *American Journal of Preventive Medicine* 35, no. 2 (August): S96-115.

- Strathern, Marilyn. 1988. *The Gender of the Gift: Problems with Women and Problems with Society in Melanesia*. Berkeley: University of California Press.
- Strathern, Marilyn. 1990. *Negative Strategies in Melanesia*. Edinburgh: Scottish Academic Press.
- Strauss, A. L. 1987. *Qualitative Analysis for Social Scientists*. Cambridge: Cambridge University Press.
- Strauss, Anselm L., and Juliet M. Corbin. 1990. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Thousand Oaks, CA: SAGE Publications.
- Theeke, Laurie A. 2010. "Sociodemographic and Health-Related Risks for Loneliness and Outcome Differences by Loneliness Status in a Sample of U.S. Older Adults." *Research in Gerontological Nursing* 3, no. 2 (April): 113–125.
- Timmermans, Stefan. 1999. *Sudden Death and the Myth of CPR*. Philadelphia: Temple University Press.
- Valtorta, Nicole K., Mona Kanaan, Simon Gilbody, Sara Ronzi, and Barbara Hanratty. 2016. "Loneliness and Social Isolation as Risk Factors for Coronary Heart Disease and Stroke: Systematic Review and Meta-Analysis of Longitudinal Observational Studies." *Heart* 102, no. 13: 1009–1016.
- Zee, Jerry. 2017. "Holding Patterns: Sand and Political Time at China's Desert Shores." *Cultural Anthropology* 32, no. 2 (May): 215–241.
- Zylstra, Bradley, George Netscher, Julien Jacquemot, Michael Schaffer, Galen Shen, Angela D. Bowhay, et al. 2018. "Extended, Continuous Measures of Functional Status in Community Dwelling Persons with Alzheimer's and Related Dementia: Infrastructure, Performance, Tradeoffs, Preliminary Data, and Promise." *Journal of Neuroscience Methods* 300 (April): 59–67.