

## Commentary

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# Ceding Control, and Gaining Freedom: Anthropological Research in the Real World

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I had just sent the final draft of an article titled “*The Real World is a Messy Place*”<sup>1</sup> which chronicled a 4 year project to assess the effectiveness of various technologies to aid in the delivery of care to individuals with developmental disabilities and severe mental illness, to my co-authors, when I realized that this was the 20<sup>th</sup> anniversary of deciding to conduct research with non-academics. It was in 1996, when I ignored the advice given by Chef in Francis Ford Coppola’s film, *Apocalypse Now*, to “don’t get off the boat” and began to undertake ethnographic research exclusively with non-academics in the real world of care provision. At the time, the decision appeared to make sense since, as an anthropologist, I had conducted fieldwork in a variety of communities around the world, so it was easy for me to rationalize that this first foray into the real world of care provision was just another field site that I would leave at some point. But this didn’t happen as I soon lost sight of the boat, then of the river and eventually got so far into the jungle of the real world that there was no longer a path back to the comfortable and safe world of academic research. I had gone native, it just took 20 years for me to realize it.

During these 20 years I’ve conducted anthropological research in over 30 different entities in 5 countries—the United States, the United Kingdom, Ireland, Canada and the Netherlands—with over a dozen different care organizations, both not-for-profit and for-profit, and numerous care models including: assistive living; dementia care; care management; visiting nursing; naturally occurring retirement communities; congregate living communities; adult training facilities; discharge planning; integrated comprehensive home health care; locked-down units for sexual predators; and outpatient clinics. I have also researched a wide range of populations including: cognitively impaired older people; human immunodeficiency virus infection and acquired immune deficiency syndrome (HIV/AIDS) patients; at-risk elderly living in the community, individuals with developmental disabilities; elderly living in assisted living facilities; older hospitalized cardiac patients; severely mentally ill individuals; community dwelling healthy elderly; and sexual predators. I have published numerous articles and book chapters on this research, along with 2 books and presented over 75 keynotes, invited lectures, papers and posters in the United States and abroad, and consulted for over half-a-dozen companies and organizations, ranging from Honeywell and General Electric to a local county care facility. I even sat on the Board of Directors of a start-up company that attempted to develop and market a product to at-risk older people living in their own residences.

## CONSEQUENCES OF GETTING OFF THE BOAT

Prior to deciding to work directly with non-academics, I had built a fairly conventional academic career. I had obtained funding from National Health Service (NHS), National Service Framework (NSF), National Investigation Agency (NIA), United States Agency for International Development (USAID), World Health Organization (WHO) to conduct anthropological research and collaborated on research and published books and articles with established anthropologists. Even when I first got off the boat, I thought that I would stay close to the shore and very quickly get back on board, but I didn’t. Instead, I wandered further and further afield, to the point where I actually lost interest in even trying to find the boat, let alone getting on board.

This is not to say that my journey was always easy and that I didn't experience a degree of culture shock, but it was never dull and I learned some useful lessons along the way.

### **ANTHROPOLOGICAL RESEARCH VS. "ANTHROPOLOGICAL RESEARCH"**

When I began working with non-academics, I assumed that conducting research would be little different in the real world as it was in academia. I was wrong, oh so wrong. Perhaps I was naive or maybe it was my inexperience, but I quickly realized that I had entered a vastly different culture in which a different set of rules applied and that this culture was not going to change and that, if I wanted to work in this culture, I was the one who had to change.

One of the first things I had to change was my expectation that I would be in control of the research process. When I conducted conventional ethnographic research I was in control. Yes, I had to conform to what the granting agencies wanted and compromise with my co-PIs, but to a great extent I was in complete control. I developed the timeline, chose the population, selected the sampling design, created the data gathering instruments, picked the appropriate data analytical tools and decided when I believed I was ready to publish the findings.

Once I started conducting anthropological research with non-academics, I lost control over almost every aspect of the research endeavor. I could make suggestions, but the final say was in the hands of people at the organization or company. They decided when the research began and ended, who would be included in the study, the data gathering instruments and determined if the findings were to be published and even if their decision was positive, had final say on what could be included or not, even extending to the words used to describe the research process. Three brief examples illustrate what can happen when control is ceded. In one study, I was prepared to use standard ethnographic methods—participant observation, and both structured and open-ended interviewing—to assess the use of a monitoring device used by a visiting nurse organization to track the well-being of at-risk elderly living in their own residences. Less than 2 weeks before the study was to begin, I was informed that the elderly population was to be replaced by individuals with end-stage HIV/AIDS. When I asked why the change had been made, the director of the organization just stated that they were at greater risk than the elderly population. When I responded that, since I was a gerontologist, I knew next to nothing about individuals with HIV/AIDS and would need to change many, if not all, of the instruments I had prepared, she just responded that this was a clinical decision and that was that.

In a second study, I suggested that the best way to effectively collect the data needed to evaluate the success of a specific treatment protocol was to have the home care personnel enter the care that they provided on smartphones. In this way, the data could be efficiently collected, transferred, catalogued and pre-

pared for analysis. This plan was summarily rejected because the personnel did not want to change how they did their jobs, which included filling out paper forms that remained in the residences of the individuals receiving the care. When I pointed out that if the information was in homes to which I did not have access, I would not have the data I needed to evaluate the effectiveness of the care and services being delivered, I was informed that my "research" was not worth disrupting the normal way things were done and that I would just have to find another way of collecting the information.

Even when my research had been successful to the point where there were findings that could be presented at meetings and published, I could not proceed as if I was in control. More than once, there was a request from one or more members of the care organization to be included as co-authors or co-presenters, even though there was no pretense that any of them were going to be doing any of the writing. On more than one occasion, it was my co-author who presented my PowerPoint at a meeting, even though she had not contributed more than a few editorial suggestions, usually concerning acceptable and unacceptable nouns to describe the individuals participating in the studies.

### **UNEXPECTED BUT TANGIBLE BENEFITS**

I could present other examples of how I had to cede control when undertaking ethnographic research, but this would be overkill and it would detract from the discussion of the benefits that I derived from working with non-academics, because there were definite benefits. The 2 most striking and unexpected benefits were that I no longer had to seek funding for the research nor did I have to worry about my university's institutional review. When I was first asked to conduct research in a non-academic site, I really didn't even ask where the money came from to actually conduct the research, I just pitched in and did what came naturally. After several months, I asked where the money came from and was told that the research was self-funded. The director of the organization believed that she needed to enhance the way care was being delivered and needed to track the changes to determine if the change in care models benefited the organization's clients and was cost-effective. As a result, not only was money made available to pay, for example, my time, but for equipment and other resources. In addition, staff was expected to contribute time to the project and to recruit clients to participate. It was nice to not have to worry about paying research assistants, recruiting subjects or even filling out forms so I could spend money and eventually being grilled by a program officer about expenditures.

I thought that this was a one-off experience, but I was wrong; once I was in this care network, I moved from one organization and one care model to another, never having to write a single grant proposal. Sometimes projects were self-funded, often organizations had received funding from foundations to undertake the project, sometimes private for-profit companies provided the money so that their products could be evaluated,

but regardless of the source of the funding, I was not responsible for obtaining it. This, of course, contributed to my loss of control as I became an “employee” and had to defer to the desires of the organization or company. However, I was an “employee” who was not dependent on the money because I was still employed by my university, so I could pick and choose which projects to undertake.

The real benefit of not having to search for funding was the time I gained. Not only did I not have to write proposals, and then rewrite them, but there was no longer that interminable delay between getting the idea for a research project, writing the proposal and waiting for the funding, if it came, in order to start the research. When I agreed to work on a project, it almost always started right away; sometimes actually quicker than I would have liked, but there was never the usual waiting associated with trying to obtain funding to conduct my more conventional anthropological research. And I must admit that I became addicted to the speed of projects moving from inception to initiation in weeks and not months or years.

The other unexpected benefit of working directly with care providers, I did not have to submit my work to my university’s medical faculty dominated Institutional Review Board (IRB). Whether a hospital, a visiting nurse service, an assisted living facility or a care management company, all of them had their own review boards and it was someone else’s job to get the research project approved, not mine. I often had to submit supportive material along with the instruments that I proposed to use to collect data, but I did not have to submit and resubmit my proposal and once again experience delay, waiting for the next meeting of the IRB.

Of course, not submitting my work to my university’s IRB had some repercussions, the most consequential being that I could not use any university resources in my research. At first this appeared to me to be a real handicap, because I couldn’t use graduate students to help in the collection and analysis of data, the university’s computer center or any other resources. However, I very quickly came to realize that this was not necessarily a bad thing. For example, as every academic researcher knows, using graduate students in research is a mixed blessing, since their major responsibilities are class work, writing papers and taking exams, often resulting in them not being available when they are most needed. Employees at the organization, on the other hand, are at the organization full time and have a buy-in to the research that graduate students can never have. Yes, employees have to be trained and not all will be fully committed to collecting the data, but overall I have found that they are, when it comes to collecting data, at least as dependable and effective as graduate students. As for analyzing data, 20 years ago not having access to my university’s main-frame was an inconvenience, but not a deterrence to crunching my data. Today, given the advances in computing and software, I can do at home on my own PC what I need to do with no real problems or delays.

The one issue that was a major concern I had to conform to my university’s policy on consulting, which allowed me only one day a week. Of course, there were holidays, weekends and the summer in which I could work as much as I wanted and thus, it was more an issue of scheduling, than a lack of time on the research. The key to keeping my university’s administrators happy was retaining the level of publications and professional activities the same as before I left the boat. This turned out to be a challenge for reasons that I, once again, did not anticipate.

## PUBLICATION CHALLENGES

I assumed that I would be just as successful in publishing the results of my increasingly non-academic research as I had been in my more conventional anthropological career. This turned out to be naïve, as I quickly discovered that the type of ethnographic research I was doing was seen by many reviewers as being way too far off the boat for publication. The reasons varied somewhat, but in essence all came back to the lack of another type of control: control of the parameters of research. I should have seen this coming, since during my first non-academic projects a colleague I was trying to recruit to help me in data analysis, experienced so much frustration in the type of data I collected that he stated with great exasperation, “*the data keeps changing, how do you expect me to analyze it*” and walked away from the project. I didn’t even get a chance to explain to him that the data were changing because of the nature of the population—older post-surgery cardiac patients who had been in the hospital for at least 19 days—and the very flexible interview schedule being used to capture the information that appeared relevant to track recovery after discharge. I had no control who was included in the study—the discharge planners selected them—I had little input into the questions asked—the cardiac surgeons had the most input—and it was very difficult conducting follow-up interviews once the subjects were out of the hospital because of their age and health status. Thus, there was missing data, variation in the timing of the follow-up interviews, frequent re-admittance to the hospital and significant subject attrition (death). By any standards, the data set was less than pristine, but I was elated that there was any information at all and the hospital staff was excited that they had concrete, if messy, data they didn’t have before. What we were able to find helped the discharge planning staff refine their care model, which was the goal of the project, in the first place.

What I thought was an anomaly turned out to be the norm, over time, as instruments I used, selection criteria for subjects I employed, data that I collected, and analytical techniques I applied, were continually defined as not methodologically “rigorous” enough by journal reviewers. It’s not as if I didn’t know and use appropriate anthropological methods used in more academic research. For example, I had used sophisticated sampling frameworks in my ethnographic research. Even under extremely challenging conditions when conducting anthropological research in Somalia, I used a random sampling to select villages for inclusion in the study and for household heads to interview.

But once I began to work on the ground with care providers, I had to alter my entire view of what constituted a reasonable population to study, which turned out to be whatever population the care providers deemed the most important. The need to find solutions to real world problems, in my mind, if not the reviewers, trumped the need for purity in the methodologies I employed. Ultimately, my solution was to seek out journals that were more focused on publishing work on the evaluation of the actual delivery of care.

### NOISE IS NOT ALWAYS BAD

But the entire experience of struggling with reviewers led me to an interesting conclusion: what most researchers see as noise, I view as the most important research component. By noise, I mean that internal validity is compromised by the interaction of research variables, e.g., selection criteria not being randomized, the data collection instruments being subject to change over time, thus contaminating the data. In the ethnographic research that I have conducted in the real world, I've never had the luxury of using any form of sampling, simply because the populations have been too small and fluid. As for maintaining the sanctity of the questionnaires, surveys and interview schedules that I have employed, I gave up any attempt very early in my journey. If a question did not result in data that could help in the assessment, it was quickly jettisoned and others added, violating one of the basic tenets of anthropological research. The reason for this violation was simple: the goal of the research was to obtain information that could be used to assess the effectiveness of the care being delivered, not maintain purity. In addition, I have never tried to keep the objectives of the study from the participants nor employed control group—all violations of standard research practice. And why have I ignored these protocols in my real world research, whereas I consistently applied them in my academic work? Simply because the goals of the research were so different. Academic research is conducted primarily to impress other academics with the rigor of the methods employed and to convince granting agencies that you are worthy of funding. The goal of the anthropological research I've been involved in for the last 20 years is to explore ways and means of delivering better, more timely and cost effective care to a particular patient/client population. It is a question of solving problems, within a very limited time-frame and budget, and everyone involved understands that there have to be compromises.

In many ways, the attempt to eliminate noise is another control issue with the researcher defining things that get in the way of a perceived clean analysis. Almost a decade ago, I wrote an article with a colleague titled, *Embrace the Chaos, It's not Noise: Lessons Learned from Non-Traditional Environments*,<sup>2</sup> and presented similar ideas at a series of workshops, national and international conferences, and professional meetings of care providers. The response to the article and the talks was extremely informative. Academic audiences responded, as I expected, fairly critically to my methods and claim that noise should not be filtered out of research but, instead, should be seen as an im-

portant source of information. It was at these discussions that I first realized that the key issue was one of control of the research process; as long as the researcher could filter out the self-defined noise, the more control that she/he had, and the more chance of statistically significant results being the outcome. When I pointed out that statistically significant results often had nothing to do with "significant" real world results, i.e., findings that could be used to improve specific aspects of care provision, my arguments were summarily dismissed.

On the other hand, when I presented this same argument to care providers they were largely confused by my differentiation between academic and real world significance. These were bright, sophisticated care providers, many of whom had participated in research at some point in their careers, but they could not understand why academics were so concerned about standard deviation rather than with findings that could have a real impact on the care that was provided to their clients/patients. Of course, being an academic myself, I felt compelled to defend why so many of my colleagues were so obsessed with research for research's sake by pointing out that academic research has resulted in findings that had an impact in the real world. This argument was politely dismissed and I quickly realized that I was figuratively trying to unite two groups with vastly different world views and that I was not going to convince either that the other had merit, so I gave up and just went about more work.

### WHERE THINGS STAND

It is not correct to say that I completely gave up, because I'm still advocating for more academic researchers to get out of the safe, controlled environs of the university and apply their skills in the real world of care provision; but it is a hard sell. Although normally I'm not that reflective, I have had to think about why I have been willing to continuously engage in research where I have so little control. I think that 2 things drive me to this work: freedom; and trying to make a difference. In a strange way, the freedom that I experience engaging in this non-academic research is the result of me giving up a quest for control. Yes, as I explained previously, I have little control over the specific topic to be studied, the research calendar, subject selection, publication and presentation outlets and the methods employed, but in turn, I can spend almost all of my time actually collecting and analyzing data. I'm free from trying to please granting agencies, negotiating with the university's IRB, stoking the egos of my co-PIs and other academic researchers, running after money to support a large academic research structure and, perhaps most importantly, free from waiting around to get the money and receive the permission that allows me to start collecting the data. From my perspective these benefits far outweigh the need to cede control and this is before I add in the second reason for my willingness to go so far from the boat: my work can and actually has helped improve the delivery of care.

In a time long ago and what seems like a different galaxy, I scoffed at using social science research to help people in

the real world. My exact feeling that I expressed for close to 2 decades was, “if you want to help people become a social worker”. I now believe that I was wrong or misguided or just full of myself, because for most of the last 20 years I have been telling my students and younger anthropological colleagues that if their research is not helping people beyond the hallowed halls of their universities, they are just wasting their time. It probably sounds strange to many academics when I say that I get much more pleasure when my research impacts the way care is delivered than I do having an article accepted for publication, but it does. Does this make me a social worker? No, but it does make me a social scientist who believes that his work should be socially relevant and that the most relevance is gained by helping people.

This essay has become much preachier than I intended, so let me return to my main theme: more anthropologists should get off the academic boat and see what they can accomplish in the messy real world. I believe that, in many ways, the key to persuading anthropologists to conduct research in the real world is the broadening of the definition of a field site. I have argued in lectures and print over the last two decades that any social environment can be regarded as a field site in which anthropological research can be conducted. Currently, my field site is a large non-profit company that provides education and human services to individuals with special needs, e.g., mental illness and developmentally disabled. No different than in a village in Somalia, I must carefully observe the relationship among inhabitants, in this case staff and clients, collect information on the various activities of these individuals, whether it is in a group home, a training facility or the company’s headquarters, analyze

the collected material in order to understand the content of the behavior observed and reach conclusions. The only difference is, rather than the conclusions being about the distribution of labor between raising sorghum and livestock, my conclusions in this field site concern the effectiveness of a new care delivery model. It’s still anthropology; it is only the field site that has changed.

I’m fully aware that few anthropologists will take even a single step off the boat and that many others will dislike the feeling associated with not being in control and immediately climb back on board while very few will either stray much beyond the shore line and fewer still will actually enter the jungle; but if even a couple do, then I will have succeeded. And if these few can persuade others that getting off the boat is worthwhile, maybe over time there will be a large enough number of researchers toiling in the real world to make a difference and, at the same time, experience the freedom that comes from not being in control.

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