

Larger than life: personal and social transitions within Type 2 diabetes

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Type 2 diabetes, a chronic illness, is reaching epidemic proportions in North America. Pharmaceutical and consumer companies alike are embracing ethnography as a means to gain insight into the condition and to meet the complex needs of diabetics. This paper explores three topics that emerged from our ethnographic work in this area. First, we discuss the contribution of ethnography towards understanding the lived experience of Type 2 diabetes. Second, we suggest Type 2 diabetes should be viewed as a meta-transition that encapsulates four types of transition, each of which is an important aspect of the diabetic experience, and which may provide critical insights in an applied context. Third, we argue that applied ethnography can be dramatically enriched by an anthropologically and theoretically informed approach, without which the experience of, and transitions within, Type 2 diabetes cannot be fully understood and the social and business benefits maximized.

Introduction

Traditionally, the health burden of Type 2 diabetes has been borne by individuals and families.¹ In this context, the notion of transitions is meaningful because every diabetic person progresses through disease stages and treatment strategies, each of which make different demands on the mental and physical resources of the person. Currently, however, we can also associate Type 2 diabetes with a very different kind of transition. As rates of Type 2 diabetes explode globally, the disease is reconfiguring from private experience to global public health crisis. This transition, and the news coverage, diabetes research, advocacy, and public debates it entails, lifts the question of *who* gets diabetes and *why* they get it into prominent view. This, in turn, has a profound impact on individual diabetics understanding of what is happening to them, their disease experience and how they approach managing their condition; it also shapes the understanding of those who do not actually have diabetes, but who may choose to adopt strategies to minimize risks. In a business application context, clients may be motivated to understand prevention or treatment strategies, depending on their product or service offering.

¹ Type 1 and Type 2 diabetes were formally distinguished in 1959. Please see http://www.diabetes.ca/Section_About/timeline.asp for an overview of the timeline of the illness.

This paper attempts to characterize the private transitions of the diabetic person and the current social transition of the disease itself, to illustrate how both affect the diabetic experience, and to indicate why this level of understanding of Type 2 diabetes is relevant – indeed essential – in applied market research. In so doing, we advocate for a disciplinarily and theoretically informed approach to ethnography that assumes that while any well-designed and executed market research project may yield meaningful insights, the richest and ultimately most applicable insights are produced by research that acknowledges the authentic complexity of an issue such as Type 2 diabetes, and that actively draws upon existing social scientific knowledge in its pursuit of answers. Our views have been shaped by a number of projects we have conducted with Type 2 diabetics for pharmaceutical and consumer goods clients who themselves have had diverse interests and business objectives. Ethnography has been a frequent component of these projects, which, while highly varied, shared as a criterion of success the need to understand the *experience* of Type 2 diabetes and the contexts in which people grapple with self-care, food choices, treatment options and regimens, familial demands, shifting emotional ground and physical suffering so that, at a minimum, clients can speak to these constituents meaningfully, and optimally, so that they can design products or services in a way that truly meet diabetics' needs.

An Overview of Type 2 Diabetes

Type 2 diabetes is a chronic degenerative illness in which the body slowly becomes unable to produce or to use insulin. The disease takes a terrible toll on the body. Even in wealthy countries where diabetes education and treatment are usually readily available, Type 2 diabetes typically shortens lifespan by 10-15 years, and lowers quality of life, physically and emotionally, for many years before that.

The statistics surrounding Type 2 diabetes are astonishing. The rise in incidence and the forecast increase in new patients are such that it requires little imagination to see why a hunger for insight into this area has expanded beyond traditional stakeholders such as clinical researchers and pharmaceutical companies, to include businesses as diverse food manufacturers to travel and leisure providers. For example the International Diabetes Federation, a non-governmental organization in Brussels and affiliated with the World Health Organization, reports that Type 2 diabetes “affects more than 230 million people worldwide and is expected to affect 350 million by 2025.”² The American Diabetes Association states that, counting those who currently have the disease but are undiagnosed, “20.8 million children and adults in the United States, or 7% of the population...have diabetes.”³ Type 2 diabetes represents 95 percent of these cases. A study by the Centre for Disease Control reported in JAMA states that 1 in 3 children born in 2000 will develop the Type 2 diabetes and those numbers will go higher if you are Latin American or female⁴. *The*

² <http://www.idf.org/home/index.cfm?unode=3B96906B-C026-2FD3-87B73F80BC22682A>, accessed 12 July, 2006.

³ <http://www.diabetes.org/about-diabetes.jsp>, accessed 12 July, 2006.

⁴ See Narayan, K.M et al (2003)

Everyday Life

New York Times reports that Type 2 diabetes is America's "fastest growing health problem"⁵ and that it "is the only major disease with a death rate that is still rising."⁶

Type 2 diabetes kills approximately 225,000 Americans a year and is the "leading cause of kidney failure, blindness and non-traumatic amputation."⁷ Also deeply troubling is the fact that the average age of onset for Type 2 diabetes is getting steadily younger, so much so, that it is no longer referred to as "adult onset diabetes". More of us will be living with the disease and its devastating complications for longer. The ultimate manifestation could be its impact on longevity itself – during the previous century the human lifespan in North America has been steadily rising – diabetes could begin to shorten that average life span by as much as 10-15 years.

Diabetes and its Transitions: Personal Experiences and Social Discourse

Personal Experience

People don't really care that much. You tell them [and they say], "Yeah, I got an aunt who's diabetic, I've got some relative who's diabetic, they all know somebody who is diabetic. But they don't know what the impact of that is." (Alice, 51)

What is it like to be one of these numbers? For patients, perhaps the most significant aspect of Type 2 diabetes (and one that has considerable implications for market researchers) is its chronicity.⁸ People who develop Type 2 diabetes have it for life, which means always living with symptoms or the fear of them, and also managing a burdensome self-consciousness about all daily choices – from the food one eats to where one can safely go on holiday – that could affect one's diabetes management.

The demands and toll of living with Type 2 diabetes ultimately affects so many aspects of their lives that we have come to view the disease as a meta-transition, within which a host of related transitions play out. The physical effects of the illness, though they may vary from person to person, are essentially linear, that is, the disease gets progressively worse over time. Typically, this inexorable transition, and how patients, healthcare providers or commercial stakeholders can best manage it, draws the most focus in the clinical

⁵<http://www.nytimes.com/2006/05/17/nyregion/17diabetes.html?ex=1152849600&en=4a8fe23da6d4ea08&ei=5070>, accessed 12 July, 2006.

⁶<http://www.nytimes.com/2006/05/16/health/policy/16diabetes.html?ex=1152849600&en=866cc8cd04456ffc&ei=5070>, accessed 12 July 2006.

⁷ *Ibid.*

⁸ See Kleinman (1988), Mattingly & Garro (2000) and Heurtin-Roberts & Becker (1993).

literature, and indeed is a primary concern in market research. Although our scope in this paper is wider, it is essential to consider this most fundamental aspect of the disease experience.

At the outset of the illness, Type 2 diabetes is typically asymptomatic, and people may only find out they have it during the course of routine check-ups or treatments for other illnesses. On one level, patients may be dismayed to hear that they are diabetic, but after the initial shock wears off, many may question whether they *really* have it, or if it is really as serious as their doctor says: after all, they feel fine, so how bad can it really be? Sydney's story is illustrative of both this view and the consequences. Sydney is a 59 year-old diabetic living in a major North American city. He is college educated, worked in a professional administrative capacity until he took early retirement, and through insurance, has access to high-quality healthcare.

I remember 15 years ago [the doctor] was telling me I'm borderline and he had a big sign on his office about diabetes and the effects but I was borderline, I liked to eat. I wasn't physically feeling any effects so I tended to ignore it.

However, left untreated Type 2 diabetes will soon start to take its toll. For Sydney, this meant that he had seven relatively trouble-free years, then:

I developed an ulcer on my toe, which was the first real problem. That one eventually healed although they didn't tell me at the time I was a candidate for amputation.... A couple of years later...I sort of amputated my own toe. It's funny now but I remember I was cutting my toenail and remember earlier I said I think the word is necropathy [sic] where you didn't have the feeling; I was cutting my baby toenail and unknown to me I was cutting the flesh and not the nail.

The healthcare team treating Sydney saved that toe, but shortly thereafter he developed an ulcer on another toe that refused to heal, which necessitated amputation. When we met with him, Sydney had recently successfully fought off another amputation, but was struggling with shortness of breath, fatigue and other health concerns that made mobility difficult. Although he expressed the hope that his immediate situation would improve enough to return him to his former energy levels and mobility so that he could pursue modest travel and other activities he had anticipated in retirement, he seemed accepting of a certain diminishing of possibility. Diabetes was his future, and was written into his body.

Sydney was employing two treatment strategies typical for his stage of Type 2 diabetes: dietary management and oral medications. In Type 2 diabetes, the immediate goal is always to control blood sugar levels, and secondary goals are to minimize the risk of the impact of symptoms (such as Sydney cutting his toe because he couldn't feel it) and managing frequent co-morbidities such as high cholesterol, obesity, high blood pressure and depression. The treatment options for diabetics revolve around two principles: self-care

Everyday Life

and pharmaceutical intervention. Self-care refers to managing one's diet, exercising, regular monitoring of blood sugar levels, frequent checking of toes and extremities for ulcers or wounds, and scheduling regular visits to health treatment professionals, be they family physicians, endocrinologists, diabetes clinics and so on. Health care professionals may encourage pre-diabetics and early stage diabetics to try to manage their blood sugar levels exclusively through diet and exercise, only moving to more aggressive treatments if that appears to fail, or if, notwithstanding significant behavioral change, a patient's blood sugar levels remain high or unstable, and the diabetes continues to progress.

There are two classes of pharmaceutical therapy: oral medications and insulin. Oral medications work on two principles: boosting the amount of insulin in the bloodstream, or helping the insulin in the blood stream work better.⁹ Because they work differently, patients may take both kinds of oral medication simultaneously. Physicians prescribe insulin for Type 2 diabetics if their blood sugars are not controlled with diet, exercise and oral therapies. Patients typically inject insulin, but may also use insulin pumps or inhalers. Type 2 diabetics can have highly varied responses to arriving at the point of insulin injection: some may loathe the real or perceived stigma of injection, whereas others may appreciate the greater level of control it delivers.

The physiological and treatment transitions that Type 2 diabetics experience are a natural focus in diabetes research. However, research that focuses only on this aspect of the diabetic experience risks missing the significance of the lived experience of diabetes, and with it, challenges and opportunities for businesses seeking to reach diabetics or those who care for them. Anthropologically informed literature¹⁰ on diabetes reminds us that diabetics struggle to incorporate the disease into their sense of personhood and indeed, into their whole lives. In our experience, it is often this latter emphasis that preoccupies diabetics and defines the diabetic experience. This reality highlights the contribution that an anthropological approach and sensitive ethnography can make in the quest to understand Type 2 diabetes. Witnessing the context in which people are managing diabetes, and using this to expand upon what they tell us about living with the illness, brings us closer to their reality and the physical and emotional needs and wants with which they struggle, and which present raw opportunity areas for businesses.

In respect to emotional and social transitions, then, the central tenet is that while physiological and treatment transitions are linear, the emotional and identity transitions are recursive. The chronicity of the illness, the imperatives of self-care, diabetes discourse and of course physical decline work individually and together to set a stage on which Type 2 diabetics face a number of emotional assaults. People respond to these challenges in different ways depending on their inner and external resources, and even at the individual level, over the course of one's illness. Some diabetics may get "stuck": while their physical

⁹ <http://www.umassmed.edu/diabeteshandbook/chap09.htm>, accessed August 24, 2006.

¹⁰ See, for example, Ferzacca 2000, Hunt 1998.

disease progresses they remain emotionally paralyzed. For example, Alice, a youthful fifty-four year-old professional, told us that, despite living with Type 2 diabetes for a decade:

It still feels like it's pretty raw. It causes me to feel depressed every day. I wake up thinking why do I have this? I see these old guys in the bars here drinking beer, smoking cigarettes and I know I can't do that. I've got my little machine and all these little frickin pills, and like how come I've got this when other people, like the lady downstairs, she's 81 years old, she eats and drinks, she has 14 eggs a week.... It's very hard to be strict all the time and I feel that's what I have to do to keep on top of it.

Alice is actively trying to manage her condition. She regularly seeks new diabetes information and support to help her manage her diabetes. However, the seeming unfairness of the illness, frustrations with managing it, and the uncertainty that it throws over her future, have devastated Alice emotionally, and any setback in self-care or progression of the illness reinforces the rawness she feels. Further, cycles of frustration and depression also invite recursive denial. Healthcare providers and market researchers occasionally express mystification that some Type 2 diabetics simply do not appear to take their illness seriously enough to manage it aggressively, even after symptoms start to appear. Alice, however, explained to us that despite waking up with diabetes on her mind every morning, she still felt that she was in “some ways in denial.” Diabetes was simply too big.

Further, the constant pressures of self-care itself can take a significant toll emotionally on diabetics. Because self-care is a cornerstone of diabetes management, healthcare providers routinely emphasize the importance of blood testing, food management, and if relevant, weight loss. All of these areas are potentially fraught for diabetics. For example, some diabetics avoid monitoring their weight or blood levels if they think the results are going to be “bad”. Alice, who had the accoutrements of self-care – a blood monitor, an elliptical machine, and self-help books – prominently on display in her apartment, had avoided weighing herself for several weeks prior to our visit because she was “afraid” of the results. Further, as Ferzacca (2000) has documented, diabetics may adopt strategies, such as avoiding full disclosure to their physicians, or fasting for the day before a physician’s visit in order to get a desirable blood sugar reading, for fear of being upbraided. Sydney himself practiced this very tactic to avoid, as he put it, “getting heck” for failing to manage his condition.¹¹ In both cases, an emotional imperative – not to be “in trouble” – trumps the imperative of self-care.

There is a clear moral dimension to this process – which, as we will see in the following section, is profoundly tied to the wider social discourse about Type 2 diabetes. Self-care, optimism and control are the by-words for “good” in diabetes management; lapses, vacation, depression and failure to control are the by-words for bad. Alice explicitly makes this connection, albeit it in a very personal frame of reference:

¹¹ Sydney would subsequently reward himself for his forbearance, and for having endured the physician’s visit, with a large plate of bacon and eggs.

Everyday Life

My whole life my mother has been, you're lazy, you're lazy, and when I don't take my pills and when I eat what I'm not supposed to, then I feel like I'm that lazy kid again, I'm not doing what I am supposed to do.

Arguably, this exerts a further emotional toll in so far as the diabetics may chastise themselves, or be chastised, for being visibly out of step with North American values of optimism and productivity.

Type 2 diabetics also typically find themselves grappling with social transitions in which aspects of their identity and social roles may be challenged. Hunt and Arar (2001) have documented the struggles some women face as the requirements of self-care conflict with their ability to fulfill their role as caregivers to others.¹² We have also found that diabetes reaches into familial relationships in powerful ways. For example, Victoria told us that she has told only her two sisters about her diabetes, despite the fact that she sees her wider family frequently. The reason is simple: she wants to avoid being treated like a child by her wider family or friends:

I think there's a perception of diabetics and it's not a positive one. If people know you're diabetic, then [they ask questions like] "should you be having this dessert?" I'm a grown woman. I don't want someone to make that choice for me.

Other diabetics describe transitions within household roles as they seek to find ways to accommodate diabetes within the family. For example, John, a thirty-nine year old diabetic father of twin girls, told us that he was concerned about providing a role model for his daughters:

I think part of it too is our kids haven't had good modeling for what is healthy behavior. I don't think they understand what diabetes is, what their Dad has, and so they see me eat good and eat bad, so I'm not necessarily giving them the good signals too.

Meanwhile, John's wife, Mary, noted dryly that John relieved her of grocery shopping duties a long time ago because she didn't buy "good stuff", even though "he buys just as much crap."

In sum, Type 2 diabetes, a physiological illness, is itself a meta-transition in a patient's life. Despite its innocuous and asymptomatic beginnings, the disease will eventually progress. If a patient has access to healthcare, his or her treatment strategies will attempt to keep pace with the disease. But while these aspects of diabetes rightly attract a great deal of attention from researchers, the less noticeable but also deeply felt emotional and social transitions are also essential components of the diabetes experience. However,

¹² See Hunt and Nedal (2001).

the fullest understanding of the experience of Type 2 diabetes requires a further step: viewing it from a social as well as a personal perspective.

Social Discourse

Type 2 diabetes can strike anyone, but unlike Type 1 diabetes, which appears to be purely genetic in origin, the etiology of Type 2 diabetes is more complex. In North America, people of Hispanic, African-American and Native American descent are particularly at risk, suggesting the possibility of some genetic predisposition; however, overwhelmingly the key risk factors associated with the disease are low socio-economic status, obesity and inactivity.¹³ Because of this, Type 2 diabetes is frequently tagged a “lifestyle” disease and is embroiled in North America’s heated discourse about the rise in obesity. Commentators typically invoke a number of arguments here. The first, and perhaps most generous, is strongly social determinist: conditions, such as the prevalence of fast food and dearth of resources to encourage physically active leisure and play (public school grounds, safe parks, etc.) conspire against already disadvantaged Americans to make them heavier and sicker. At the opposite end of the spectrum, the less generous argument is that obese and diabetic Americans are greedy and out of control, quite literally eating themselves to death, fitting symbols of gluttony, consumption and even – stretching it – the rise in personal and national debt.¹⁴ In both of these arguments, Type 2 diabetes is configured as a social exemplar of something gone wrong, although the former is more likely to absolve the individual of responsibility and the latter somehow seems to contain the notion that the individual should be able to chart a different course if he or she had sufficient backbone.

The social discourse has at least three immediate and interrelated effects on diabetics’ experiences. First, as we saw with Alice, it creates the framework for their own evaluation of their condition and management. Thus, changes within the discourse could theoretically shape transitions within diabetic patients’ emotional or social spheres, or at the very least, provide them with new and different raw materials from which to make sense of their illness. Second, diabetes discourse creates a backdrop against which others react to them. Family members, friends, healthcare providers – all those who compose a diabetic’s social and health universe – hold views, and thus behave, in ways subtly shaped by diabetes discourse and the prevailing views it may enshrine about responsibility for, and the locus of control of, diabetes.

Third, diabetes discourse directly affects such tangible issues as fundraising for research. In a recent *New York Times* article, for example, Richard Pérez-Peña (2006) described how some parents of Type 1 diabetics are seeking to differentiate more emphatically the two forms of diabetes in order to excise the stigma of Type 2 from their own fundraising efforts. Their argument is that Type 1 diabetics, who in no way can be

¹³ There is also a well-documented lay discourse that embraces stress as a key factor in diabetes. See Schoenberg et al. (2005) and Poss (2002).

¹⁴ See Lears, J (2006)

Everyday Life

blamed for their disease, are more likely to attract sympathy – and thus research dollars – than those Type 2 diabetics to whom society assigns responsibility for their condition.

Methodological Implications

Patient-focused healthcare research faces a recurring challenge of how to capture the breadth of a chronic illness experience, and in particular, to identify which aspects of that experience are most significant to patients. This challenge is complicated by the fact that, as we have seen, chronic degenerative illnesses such as Type 2 diabetes involve not only symptom and treatment transitions, but also recursive emotional and social transitions. In other words, the disease experience is always on the move, with different aspects rising to, or receding from, surface consciousness and focus, depending on the moment. Ethnography, with its focus on lived experience, context and deep rapport between interviewer and informant, is clearly a strong choice for cultivating a deep understanding of the patient experience. Used alone or in combination with other research methods, a researcher can reasonably hope that insights gleaned through ethnography will be likelier to reveal significance nuances of experience that methods such as focus groups or surveys could miss. Furthermore it enables informants to control and guide the researcher through what is personally significant about their lived experience. The interaction with the physical (home, tools, and other elements) blend with the personal and social elements, each of which can uniquely inform the ethnographer. Indeed, a rich body of social science literature on chronic illness, derived in no small part from ethnographic studies, bears this out.¹⁵

Market research based ethnography, however, typically has a built-in limitation. Our projects are usually short and intense relative to academic research, and while principles of ethnography, such as immersion in the context, may still facilitate an understanding of an illness experience, the absolute limit on time spent with an informant, or in a given context such as a diabetes clinic, can hamper an understanding of the impact of chronicity. One can try to work within these limits, or one can try to find ways to circumvent them, and to produce insights that still tackle the impact of chronicity head-on.

While there are no perfect solutions to the conundrum of chronicity, we believe strongly that some limitations can be overcome by adopting a disciplinarily informed approach to research, and by embracing a number of tactical solutions. As alluded to earlier, there is merit in devising a research plan that is informed consistently with perspectives and information drawn from other secondary research and theory. What is *de rigueur* in academic work is for some reason frequently overlooked in applied work, perhaps because of perceived time or budget constraints. We have found, however, that a focused literature review can dramatically enhance outcomes of a project. Bluntly, this is a form of existing insight that can contribute an opening level of sophistication to a research plan that might otherwise require reinvention. Further, it can help to foster the groundwork for action-

¹⁵ See Kleinman (1988), Mattingly & Garro (2000) and Heurtin-Roberts & Becker (1993).

oriented insights by building from known or established constructs, which are then applied to the specific circumstances of the client and honed into proprietary applications.

A second disciplinarily informed approach to research is to monitor the discourse that surrounds Type 2 diabetes. Raising awareness of the discourse allows the client and researcher to follow the evolution of a socially-embedded illness such as Type 2 diabetes. This not only fosters greater understanding of the illness experience, but practically paves the way for clients to have better communications with their stakeholders at all levels, be they through advertising campaigns, literature for physicians or patients, or training their sales staff.

Moving to tactics, a good place to start is with the careful selection and recruiting of persons from various stages of the illness. However, defining the most helpful stages may not be a straightforward process. The client's needs and target market are obviously a first orienting point; for example, a pharmaceutical device manufacturer may wish only to glean insights about insulin dependent diabetics, or a food company may wish to target specifically newly diagnosed diabetics. However, one may also wish to consider segments elsewhere on the spectrum of chronicity, in order to capture insights that transcend physiological and treatment issues, and by comparison, to pinpoint what, if anything, is unique to the "snapshot" in which the client is interested.

Another helpful tactic for managing chronicity is to layer one's methodological approach. We have used self-ethnography very successfully to this end, empowering informants to tell their own diabetes story into a journal composed of highly engaging and creative exercises. Our self-ethnographies always have three critical components: "grounding exercises" that ask informants to describe themselves and their lives, including their past; "in the moment exercises" that focus on their immediate present and perhaps the specific aspects of their disease experience in which we are interested; and finally, "reflective exercises" that invite the informant to review what they have written, and to analyze their own experiences for insight. The structure of the exercises is designed to stimulate the informant's reflective and analytic talents, which, over the course of a week, leads the informant to self-revelation and quite literally a new consciousness of their disease experience. Although living with a self-ethnography workbook for a week is hard work for informants, and needs to be compensated accordingly, informants typically love the experience because of the self-insight they achieve. For us, their insights, as much narrative and pathography as ethnography, provide a rich addition to insights gleaned by other methods. The informant's self-analysis, together with our analysis of the total book, and comparison with other books and in-field ethnographies, typically gives rich insight into living with an illness for extended lengths of time, and captures details, such as the warp and woof of emotional and social transitions, that may be fruitful for clients.

Business Application

If the disciplinarily and theoretically informed ethnographic research that we describe leads to sound and illuminating insights into the experience of Type 2 diabetes, then as researchers we may say we have achieved a measure of success. But in the context of an applied environment, we measure full success by whether we have helped our clients with the business challenges they face, be they driving growth, spotting new opportunities, optimizing the language to connect with the consumer and so on.

While client confidentiality precludes us from providing real-world examples of insights and recommendations we have given to clients, we may at least offer some perspective on the options we believe exist to make use of the insights described here in an applied context in which the goal is to grow our clients' businesses by giving them strategies and tactics to meet real consumer and patient needs.

An orienting principle of our approach is that our clients must be partners throughout the research, analysis and strategy phases of a project, so that ultimately they can internalize the insights, envision the implications, and more easily implement recommendations. Because each client has its own preference for terms of engagement, we do not force one fixed process upon them; however, we always seek to find a formula that will work for them. For example, in pharmaceutical research where it is inappropriate for clients to accompany us on an ethnography, we may provide copies of self-ethnography books (in which informants' identities are masked) so that the client still has a sense of immediacy and intimacy with the patients. We also routinely conduct customized workshops in interim or final phases of a project, where clients spend the first part of the session absorbing the insights, and the latter part working through the implications for their business challenges, and even, perhaps, starting to flesh out solutions or new opportunities.

Clear communication is pivotal throughout this process. We eschew theoretical language, but we also trust that our clients are willing to take on complex ideas and subtle insights if there is clear value in them. While PowerPoint is a staple in debriefs, we also embrace other means of communicating insights. For us, an important element in accurately conveying insights is using storytelling and narrative to create impact. By demonstrating (even in composite form) the stories of the individuals from ethnographic research, we can add depth and texture to the insights for our clients. One highly effective technique is DVDs. These DVDs not only bring the story to life for clients, they allow clients to envisage where they might best leverage them. They also permit the stories and insights to be told again and again, even if the research team is not present.

Another key element of transforming insights into substantial business-building opportunities is to know *which* insights matter. In applied settings, all too often the fieldwork aspect of ethnography defines the process. The importance is attached to what one saw and heard. These things are important. However, as we have argued in this paper, in relation to Type 2 diabetes, we believe that fieldwork must be accompanied by robust analysis, which is,

as much as possible, informed by other features of the anthropological approach, including, among other things, literature reviews, an analysis of the discourse of the issue, and a comparative approach. Through these means, we strive to form composite understandings of issues so that, when faced with a particular challenge, we have a store of information on which to draw to understand which insights matter and where the greatest opportunity for our client lies.

Consistent client engagement and ownership, clear communication, and robust analysis that identifies which insights are most significant for a given client are thus three means by which we try to ensure that the insights we generate can ultimately drive action. The actual form that “action” takes varies between projects, but building on the discussion here, we would argue that there are two immediate, interrelated opportunity areas. The first lies within the realm of strategy, the second in tactical offerings. The key question in the former is, “What is your overall opportunity as a brand?” The key question in the latter is, “How do I realize that opportunity in the real and often painful world of the diabetic?”

Since it is impossible to separate strategy and tactics wholly, let us consider the opportunities for both that the insights raised here could open. One of the most obvious possibilities is that a brand ought to look at its offering and values and decide where within the diabetic experience its greatest area of opportunity lies. For example, is it in addressing, either through products or communications, a physical, emotional or social aspect of diabetes? Or does the opportunity lie in meeting two needs simultaneously? For example, a travel and leisure company, putting together the insight that diabetics crave respite from the constant vigilance that self-care is supposed to demand, and that diabetics may not disclose their condition because they fear being patronized by observers, could create a literal “diabetic vacation”, perhaps a cruise, that features days of delicious meals suitable for diabetics, safe activities and so on. While this example is admittedly a bit whimsical, we are actively working with our clients to develop a number of real opportunities that have arisen from looking at diabetics’ emotional and social needs.

Another broad strategic territory is for a brand to participate actively in the very discourse of diabetes. In business, we frequently forget that we participate in culture and *de facto* may have an impact on the constituents to whom we try to appeal; the opportunity lies in recognizing this and thus trying to shape, or add concepts to, the discourse. For example, investing was revolutionized by the concept of “pay yourself first” – a simple but powerful proposition. Recognizing the trends in the diabetes discourse, and its effects on diabetics, a brand should ask itself what proposition it might introduce that could speak meaningfully to diabetics’ needs and build its business? This could be all the more powerful if the proposition is linked to the brand’s own values and ethos, so that, for example, a sporting brand could contribute notions of individual empowerment and success, and a family-based consumer brand could contribute notions of the power of the collective will.

Finally, there is a significant opportunity area in the realm of brand experience. Brand experience has, of course, been something of a buzzword in the last decade, but

Everyday Life

paired against the notion of a disease experience, it becomes a far more powerful proposition than one customarily encounters. Typically, good brand managers seek to create a coherent brand experience out of their disparate touch points. The best of them may even consider additional measures, such as introducing new touch points to effect the best realization of the desired experience. But we would argue that the opportunity with Type 2 diabetes lies not in crafting a brand experience driven by company-focused considerations, but rather in allowing the brand experience to be shaped by needs stemming from the illness experience of the diabetic, in all its physical, emotional and social complexity. For example, if we know that isolation can be part of many diabetics' experiences, how can a brand experience be designed to assuage, or at least speak to, the needs that may arise from this? Perhaps it could be designed around a strategy of solidarity, which is articulated coherently across every brand touch point. For example, one might be to create engaging profiles of people living with diabetes (perhaps even with edgy, fun narratives and plot lines) that are included in medical packaging and regularly updated. This could have a dual effect of creating a sense of a community of others who share the same experience and *possibly* even generate some degree of anticipation around opening the package.

Conclusion

If the current trajectory continues, Type 2 diabetes will only broaden its global reach in the coming years. The effects will be evident on health care systems, in the pharmaceutical world, schools, communities and of course on diabetics themselves. As the disease continues to evolve, so will the *experience* of diabetes. It is therefore important for companies and marketers to understand the transitions inherent in the condition. Indeed, we believe that companies and marketers can to some degree affect these transitions, be it in terms of treatment or in the evolution of the discourse of diabetes, and that this can be converted into an important opportunity area.

Notwithstanding constraints posed by a commercial context, disciplinarily involved ethnography is a powerful means through which to understand the experience of Type 2 diabetes and to identify areas of opportunity for influence and intervention. Good research and strategy partners should work consistently to serve as a conduit between diabetics and clients. To do so, these partners need to generate good insights, identify those that are most significant, communicate them well and help to translate them into action so that clients build their businesses and diabetics get the services, products, concepts and communications that will mean the most to them, and that make their illness experience more manageable and bearable.

Notes

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References

- Ferzacca, S.
2000 “‘‘Actually, I don’t feel that bad’’: Managing diabetes and the clinical encounter. *Medical Anthropology Quarterly* 14(1):28-50.
- Heurtin-Roberts, S and G. Becker
1993 Anthropological perspectives on chronic illness: Introduction. *Social Science and Medicine* 37: 281-283.
- Hunt, L.M., Pugh, J. and Valenzuela, M.
1998 “How patients adapt diabetes self-care recommendations in everyday life.” *The Journal of Family Practice* 46(3):207-215.
- Hunt, L.M. and Nedal, H.A.
2001 An analytical framework for contrasting patient and provider views of the process of chronic disease management. *Medical Anthropology Quarterly* 15(3): 347-367.
- Kleinfield, N.R.
2006 *Bad blood: Diabetes and its awful toll quietly emerge as a crisis.*
<http://www.nytimes.com/2006/01/09/nyregion/nyregionspecial5/09diabetes.html?pagewanted=print>>, accessed 9 January 2006.
- Kleinman, Arthur
1988 *The illness narratives: suffering healing and the human condition.* New York: Basic Books.
- Lears, Jackson.
2006 The American way of debt: we moralize about it. Then we borrow. *The New York Times*, June 11, 2006, Section 4, p. 13.
- Mattingly, Cheryl and Linda C. Garro, eds.
2000 *Narrative and the cultural construction of illness and healing* Berkeley and Los Angeles, CA: University of California Press Ltd.
- Narayan, K. M. Venkat, MD et al.
2003 Lifetime risk for diabetes mellitus in the United States. *JAMA* 290 1884-1890.
- Pérez-Peña, Richard
2006 Beyond ‘I’m a Diabetic,’ little common ground.
<http://www.nytimes.com/2006/05/17/nyregion/17diabetes.html?ei=5070&en=df6e6e098073b27&ex=1157256000&adxnnl=1&adxnnlx=1157132307-Z0v+8qvXXXpm/FpEBE2Vyw>, accessed 10 July, 2006.

Everyday Life

Poss, Jane.

2002 The role and meaning of “Susto” in Mexican Americans’ explanatory model of type 2 diabetes. *Medical Anthropology Quarterly* 16(3): 360-377.

Schoenberg, N.E., et al.

2005 Situating stress: lessons from lay discourses on diabetes. *Medical Anthropology Quarterly* 19(2): 171-193.

Web Resources

http://www.diabetes.ca/Section_About/timeline.asp, accessed 12 July, 2006.

<http://www.diabetes.org/about-diabetes.jsp>, accessed 12 July, 2006.

<http://www.idf.org/home/index.cfm?unode=3B96906B-C026-2FD3-87B73F80BC22682A>, accessed 12 July, 2006.

<http://www.nytimes.com/2006/05/17/nyregion/17diabetes.html?ex=1152849600&en=4a8fe23da6d4ea08&ei=5070>, accessed 12 July, 2006.

<http://www.nytimes.com/2006/05/16/health/policy/16diabetes.html?ex=1152849600&en=866cc8cd04456ffc&ei=5070>, accessed 12 July 2006.

<http://www.umassmed.edu/diabeteshandbook/chap09.htm>, accessed August 24, 2006.