CHAPTER 6

Perspectives on Diabetes and Obesity from an Anthropologist in Behavioral Medicine

Lessons Learned from the "Diabetes Care in American Samoa" Project

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From 2006 to 2012 I was a co-investigator on a translational research project that adapted an existing diabetes self-management intervention based in the United States and implemented it in American Samoa. I am an anthropologist trained in behavioral medicine, and during the project I developed a strong appreciation for how anthropological perspectives on human health behavior can contribute to behavioral health research. This chapter articulates some of the tensions I perceive between my two disciplines. Anthropology and social science perspectives could, I argue, contribute more fully to behavioral medicine research generally. Furthermore, I will provide concrete suggestions as to how anthropology and social science can be crucial in shaping the effective development of models for health behavior change in collectivist or sociocentric cultural contexts.

"Diabetes Care in American Samoa"

"Diabetes Care in American Samoa" was an NIH-funded translational research grant testing the effectiveness of an intervention designed to help Samoan diabetes patients develop and maintain the self-management activities essential to living with this difficult chronic disease. Results published elsewhere (DePue et al. 2013).

In this randomized controlled trial, participants received regular visits from a team of community health workers and a nurse case manager. The team coun-

seled them about healthy diet and exercise behaviors and also helped them learn about diabetes, understand their medications, and make and keep related medical appointments (McGarvey 2009; DePue et al. 2010). Diabetes Care in American Samoa (DCAS) is an adaptation of Project Sugar 2, a successful diabetes intervention conducted with African-American patients in urban Baltimore, Maryland (Gary et al. 2004; Gary et al. 2005).

To translate that intervention for Samoans, the project first conducted formative qualitative work, including focus groups with diabetes patients to hear about their experiences living with, and getting care for, their illness. We also conducted individual interviews with clinic staff and providers about their experiences providing care to people with diabetes. As behavioral researchers are trained to do, we sought to identify the barriers and facilitators of diabetes care and identify effective local strategies for disease management with input from the local research staff of four community health workers and one nurse case manager; we created intervention materials and adapted protocols.

This formative research and analysis also prompted us to incorporate appropriate collectivistic cultural components to the materials and trainings we gave to the staff. For example, we emphasized the role of family and encouraged the staff to enlist family support during intervention visits by inviting all family members to participate in them. In addition we problem-solved with focus group participants about the dietary challenges they encountered at Samoan cultural occasions. We included quotes from the focus groups and interviews throughout the intervention materials; we sought to give those materials a local voice to make them appropriate and useful to participants (DePue et al. 2010).

The intervention focused on enabling staff members to support diabetes selfmanagement in their patients. But since those formative focus groups and interviews were conducted and initially analyzed in 2007-2008, I have begun to question whether self-management, a common component of behavioral interventions, is the most effective way to approach Samoan health behavior. The anthropology of the Samoas, and other Pacific Island communities, suggests that the cultural construction of health extends beyond individual well-being to balance in one's social relationships (Capstick et al. 2009; Mishra et al. 2003; MacPherson and MacPherson 1990; Norris et al. 2009). Shared food consumption, along with informal and formal communal behaviors related to diverse domains—from religious congregations to village and extended family settings—are ways American Samoans create and maintain those relationships. Asking people to eat, move, and behave differently from others, even for health improvements, may put those relationships at risk.

Diabetes self-care requires intense individual-level behaviors and time management, which in turn may decrease available resources for culturally salient sociocentric or communal relationships that are the cornerstone of health for many Pacific peoples. While the steps of self-care are necessary for individual health,

they may not be the most successful way to build an intervention in an environment where social health is as, or perhaps even more, important than physical health. Yet when I began to look for alternative models on which to build future interventions, I discovered a paucity of health behavior theories that allow researchers to look beyond individual or self-care for intervention design.

Background: Samoa and Diabetes

American Samoa is a U.S. territory, population 67,242 (CIA 2011), located in the South Pacific about halfway between Hawaii and New Zealand. The independent nation of Samoa is just to the west, and together they form an island chain populated by the same linguistic and ethnic group of native Pacific Islanders. American Samoa has been a U.S. territory since 1900. For much of this history the U.S. military maintained a significant presence on the island. Governors were U.S. Navy or U.S.-government appointed until 1977. American Samoans are U.S. nationals, and the territory's government derives a major portion of its annual budget from U.S. Department of Interior Grant-in-Aid and other federal grants. It is designated a "medically underserved" and "health professional shortage area" (HRSA 2010).

Before World War II, American Samoans worked primarily in subsistence farming and fishing. Diabetes, hypertension, and other noncommunicable diseases were rare. The increase in dietary intake and the reduction of physical activity that are hallmarks of the nutrition transition began after World War II and accelerated from 1970 to 2000 (Baker et al. 1986; McGarvey and Baker 1979; McGarvey et al. 1993; Galanis et al. 1999; Popkin and Gordon-Larsen 2004). As a result, noncommunicable disease risk factors and prevalence are rising in both adults and children (Keighley et al. 2006; Keighley et al. 2007; DiBello et al. 2009a; DiBello et al. 2009b; WHO 2007).

Type 2 diabetes has reached epidemic proportions: in 1990 its prevalence in twenty-five- to fifty-four-year-old men was 13 percent; by 2002 it had increased to 17 percent. Among women of the same age, the prevalence doubled from 8 percent in 1990 to 17 percent in 2002. Type 2 diabetes prevalence among all adults in 2002 was 22 percent in men and 18 percent in women (Keighley et al. 2007). More recent data are not available, but in 2007 the World Health Organization reported that 47 percent of the population had been told that they had diabetes in the twelve months before they were surveyed or had a fasting blood glucose ≥ 110 mg/dl—which the report identifies as one of the highest rates in the world (WHO 2007). For comparison, in 2011 the CDC identified 11 percent of the U.S. (mainland) adult population as having diabetes (CDC 2011) (The CDC's criteria for diagnosis in the United States is ≥ 126 mg/dl, pre-diabetes is considered 110–125 mg/dl.)

The levels of overweight and obesity have likewise risen and are extremely high in the territory. Between 1976 and 2002 body mass index (BMI) levels and the prevalence of obesity increased significantly among both men and women in American Samoa. In 1976–1978 McGarvey and colleagues found that 51 percent of women were obese. In 2002 71 percent of American Samoan women were obese and another 19 percent were overweight, leaving fewer than 10 percent of American Samoan women within the range of normal BMI. Among American Samoan men the prevalence of obesity rose from 28 percent in 1976–1978 to 61 percent in 2002 (Keighley et al. 2007; Keighley et al. 2006; McGarvey 1991).

In addition to the reductions in physical activity that come with a transition away from an agricultural economy, other factors are directly connected to these increases in obesity and its related diseases such as diabetes. Food choices have changed from a traditional plant and fish-based diet to one with a heavy reliance on highly processed imported foods, resulting in higher consumption of calories, protein, simple carbohydrates, cholesterol, sodium, and saturated fat (Galanis et al. 1999; DiBello et al. 2009b). Fast food consumption has also increased, and as of this writing the main American Samoan island of Tutuila has several fast food outlets, including two McDonald's. In 2011 the local franchises began advertizing a Samoan Burger: a Big Mac sandwich to which a fried egg is added (SamoaNews 2011). Although the fast-food franchises are a recent phenomenon, high-fat non-Samoan foods have been part of the island's diet since the early twentieth century, when tinned meats imported by U.S. servicemen became high-status items used in the reciprocal food exchanges that are essential to many cultural events (Galanis et al. 1999; DiBello et al. 2009b).

Exercise levels have dropped as the shift away from agricultural and subsistence labor eliminated a regular source of physical activity (Keighley et al. 2007; Keighley et al. 2006). Although epidemiological research is underway and may provide evidence for novel genetic influences, modernization, American culture, and other lifestyle changes in the last thirty to fifty years have all contributed to the epidemic levels of obesity and diabetes (McGarvey and Baker 1979; McGarvey 1991, 1994, 2001; Keighley et al. 2007).

Samoan Concepts of Health, Body Image and the Individual

Previous body image studies among Samoan adults have indicated an acceptance of large body size. Traditionally as well as in the recent past, a larger body size was seen as beautiful and correlated with social prestige (Brewis et al. 1998; Drozdow-St. Christian 2002; Shore 1998). More recent data, however, has suggested that this pattern is beginning to shift, perhaps influenced by the increase in obesity-related diseases. Brewis and colleagues have measured rates of obesity-

related stigma in Samoa that are among the highest in the world (Brewis 2010 Brewis et al. 2011).

A variety of significant cultural barriers to healthy eating and health behavior change have been identified in the ethnographic and intervention literature of Pacific cultures. Many of these barriers were also raised by participants in our qualitative research. Food features prominently in cultural events in American Samoa, including fa'alavelave, required cultural gatherings for such life-cycle events as funerals, marriages, investitures of new chiefs, and the consecration of a new building. High calorie consumption also occurs at to'ona'i, weekly familyand village-based Sunday meals. Food at these cultural events was traditionally distributed according to status, with those of high status served first, making it particularly difficult to decline offered food (Braun et al. 2002). Fa'alavelave were identified as a source of stress by our participants, as well as in other research (Elstad et al. 2008), because they take time and require monetary contributions, sometimes making less money available for purchasing healthy food or for medical appointment and prescription co-payments. The requirement to contribute money to them is absolute, for if a household fails to make the required contribution, "this is taken as a sign of their withdrawal from the family or village circle. The threat is actually an eviction order" (Tcherkézoff 2008).

Fa'alavelave and to'ona'i are also challenging from the perspective of health behavior change for diabetes patients. Some of our participants indicated that these events relied heavily on meat, including pigs and canned or tinned meat, both of which have a very high fat content. Many of the providers we interviewed suggested strategies for healthy eating at these events, including eating traditional items like banana, taro, or vegetables with smaller portions of meat, yet acknowledged that this could be difficult.

Deeper cultural concepts contribute to the challenge of changing foodrelated health behavior. In adapting diabetes messages to the Pacific, Braun et al. observed that people had some difficulty eating in a manner different from others. There was also a belief that food is a gift that should not be refused and that feasting is an important part of the culture that cannot be altered (Braun et al. 2002). Shovic also identified related cultural attitudes about food, including its especially important role at social functions. Family activities and ceremonies center on eating, often to an excess; large quantities of food provided by the host family signified their prosperity, and guests are expected to eat lest they offend the hosts. Jessica Hardin's work highlights many related and relevant concerns about body size and the Samoan cultural ideology in which eating together and sharing food creates and sustains social relationships. In particular, the eating of heavy Samoan foods is phenomenologically connected to key concepts in fa'asamoa (the Samoan cultural way of life) including fa'aaloalo and alofa ("respect" and "love") (Hardin, this volume).

Writing in 1994, Shovic observed a heavy reliance on imported food products, including canned meat, fruit in heavy syrup, processed foods, and foods with a high sugar content (Shovic 1994). Recent research shows that this reliance on processed and imported foods continues in the region. Deborah Gewertz and Frederick Errington document the presence of inexpensive, poor-quality, and very high fat cuts of meat like lamb flaps and turkey tails, which are byproducts of industrial meat processing in New Zealand that are regularly imported to American Samoa and other Pacific cultures as a source of inexpensive, but high-fat, protein (Gewertz and Errington 2011).

The idea that American Samoans consume large amounts of food was expressed often enough in our qualitative data that it evolved into a code, which I titled simply "Samoans eat a lot of food." Over and over, clinicians and diabetes patient said some version of that phrase, so that it almost seemed to be part of their cultural identity; both an admitted problem, yet also a source of pride. The latter perhaps explains why a McDonald's advertisement touts the Mega Burger with its "extra meat patties at no cost" (SamoaNews 2010): it's a selling point to name a sandwich with added fat and protein as especially Samoan.

Other themes intermix with this notion of food consumption. One was that although previous generations may have also eaten heartily, they did not have diabetes—because they ate differently, moved more, or didn't eat *palagi* (European/white people) food. Throughout our discussions of food behavior and choices, many of the diabetes patients also showed a clear understanding that some foods are unhealthy and that they knew that overconsumption is directly related to diabetes. For example:

The life of a Samoan, like I said, it's all about food; yeah people just eat so much food. There were no disease like this [in] those days, but now, we have this disease called diabetes. Since the doctors have researched, and from what I understand it is thought that food is another cause of this disease. But from our ancestor's time, I don't know about the other fathers that are here tonight, but the truth is there was no disease like ... diabetes [in] those days. Life went on, but nowadays there are changes. Diabetes has become common, as well as high blood pressure. This is why food is so bad....

The mix of identity, frustration, and pride about the consumption of large amounts of food in our qualitative data echoes what Drozdow-St. Christian wrote in his ethnography of health in (Western) Samoa:

Samoans are remarkable eaters. They can consume monumental amounts of food every day. The food is heavy in starches, such as taro and rice, and also has a high fat content because so many dishes are prepared using beef tallow. At the same time, as a person matures into their 40s they are expected to do less and

less physical labour. The normative status which attaches to maturity means that middle-aged Samoans supervise manual labour, rather than participate directly in it. A combination of an increasingly sedentary lifestyle and a high fat, high carbohydrate diet, results in mid-life obesity in almost all Samoans (Drozdow-St. Christian 2002).

This ethnographer described the Samoan body type as a large and imposing physical presence: "a combination of mass, strength and stillness" (Drozdow-St. Christian 2002) in which adult weight gain accompanies the increase in dignity and status that occurs as Samoans age (Drozdow-St. Christian 2002; Shore 1998). Like food consumption, attitudes about physical activity are also shaped by cultural values. Elders, who hold power in this status-based gerontocracy, traditionally did not have high activity levels: "The Samoan view of age accords the diminished physical powers of the elderly a kind of cultural respectability in terms of an ideology of power that valorized passivity and inactivity" (Shore 1998). In this analysis, power comes, in part, from inactivity and from having the status to have other people move on your behalf. This concept, too, was articulated in our qualitative data:

See we have a custom here, if you are married and have kids you stay home. You don't walk. Period. And you may walk to church but they laugh at you they [say] 'oh, that [is] for the kids' [because] the kids are the ones that go play. If you are married and you are an adult you are not supposed to do those things. It is believed that you should stay at home. They look at you in a very funny way, especially the older ones. They say 'what is this old man doing?' But now they are realizing there is a lot of benefits and lot of older folks are walking. Before you [would] never see an older man or woman walk.

In these comments we see traditional concepts about food and exercise changing, perhaps brought about by the very high rates of obesity and noncommunicable diseases like diabetes.

Examining Communalism and Collectivism

As challenging as all of these barriers to health behavior changes are, there is another element that I overlooked in the initial analysis of our data: little consideration has been paid to how the communal nature of this Polynesian culture has driven health behavior management. Anthropologists eschew the application of such global terms as collectivistic and individualistic because they are overbroad and indistinct. I, as an anthropologist myself, find it problematic—and even against the spirit of relativism—to apply broad generalizations to any particular

culture or group of people. Yet these global concepts are often used in behavioral medicine, and I recognize that to participate in global public health debate and effective intervention design, we need to find language, as well as models and theories, that work in both arenas.

Within the Samoan belief system, health is communal. In this understanding, social well-being is essential to physical well being (Pollack 1992). Health is developed by several factors: being spiritually healthy, morally healthy, and in balanced social and interpersonal relationships (Capstick et al. 2009; Mishra et al. 2003; MacPherson and MacPherson 1990; Norris et al. 2009; Sobralske 2006; Hardin, this volume). When the cultural construction of health includes social relationships, individuals are not physically healthy if social relationships and requirements are not met first, and one of the ways those relationships are maintained is by eating together in a culturally relevant way.

In collectivistic cultures such as Samoa, individual goals are subordinate to those of the collective (Triandis et al. 1988), whereas in individualistic societies people define themselves according to how they are different from others, seeing the self as a set of unique internal attributes. In collectivistic cultures the self is defined according to how people are similar to, and fit in with, the larger group. The collectivistic self emphasizes status, social role, and relationships; belonging and fitting in; occupying one's proper place; engaging in appropriate action; and being indirect in communication (Shore 1982; Poasa et al. 2000). Anthropologists make a similar distinction between sociocentric and egocentric cultures (Geertz 1974) in which the Samoan self is clearly sociocentric (Mageo 1998). That self has been described as being relational, a part of an interconnected family and community, and specifically a self that is not an isolated or independent individual (Capstick et al. 2009; Hardin, this volume; Norris et al. 2009; Pollack 1992).

In behavioral and public health, we know little about how or why collectivism facilitates positive or negative health behaviors, yet some research suggests that being a member of collectivistic societies amidst modernization does in fact confer both health and well-being advantages via social support (Hanna 1998; Janes 1990a, 1990b). This raises the question of how we might harness the positive aspects of such social structures while managing negative influences on health behavior choices.

Theory and the Self in Behavioral Medicine

Diabetes is a particularly salient illness for this challenge precisely because living with it is so complex. Patients need to take medication, lose weight, change their eating habits, increase their physical activity, and monitor blood glucose levels to prevent complications such as neuropathy, retinopathy, nephropathy, cardiovascular disease, and amputations. These lifestyle changes are particularly challenging when family and cultural norms differ from the structured regimes that good diabetes control requires. In its early stages diabetes has few symptoms, so the complexity and burden of the recommended behavioral changes may actually seem worse than the disease or its complications (Wing et al. 2001). Our intervention was specifically designed to teach participants the complex self-management skills needed, and we know that understanding blood glucose changes, medication taking, and healthy food choices were challenging for many of our participants.

Diabetes Self-Management Education (DSME) seeks to support patients in acquiring the knowledge and skills to change unhealthy behaviors and to live with diabetes. DSME was introduced in the 1940s (Ford 1949; Osborne and Fisher 2008) and has become a dominant treatment paradigm. While diabetes has increased in disproportionately high rates in ethnic minority communities, DSME programs have been criticized for using a "one size fits all" approach developed for use with white populations (Osborne and Fisher 2008). The very behaviors that people with diabetes most need to change are those that are abundant in cultural meaning: eating, sharing food, moving, and attitudes about the body. Diabetes care programs need to address these cultural values, and some interventions do so (Sarkisian et al. 2003). Yet many still follow the principles of DSME, in which the self is centric and which is therefore an individualistic paradigm.

Increasingly, researchers are calling for behavioral interventions that begin with an understanding of population-specific attitudes and barriers to selfmanagement behaviors and that are informed by health behavior change theory (Glazer et al. 2006; Osborne and Fisher 2008; Sarkisian et al. 2003). Behavior change theories and models identify methods for supporting healthy behaviors and amending unhealthy ones. Behavioral scientists have emphasized the importance of using health behavior change theories to design interventions because those that do are more effective (Painter et al. 2008; Rothman 2004). Yet these theories focus on how individual cognitions and perceptions affect health behavior change. Interventions for collectivist cultures require theories that incorporate social and contextual factors. Tamasese and colleagues have observed: "The Samoan self ... is a relational self. ... [I]t cannot be assumed that developmental theories, therapeutic interventions and mental health service practices that have evolved in cultures with individual concepts of self, will necessarily be relevant for people from collective based cultures" (Tamasese et al. 2005). We attempted to address these concerns by including family members in diabetes teaching provided by our staff to program participants. We also chose a model for the intervention that allowed us to include community perspectives in adaptation, implementation and evaluation.

In a recent systematic review of the use of theory in health behavior research, Painter and colleagues found that from 2000 to 2005, three-quarters of the ar-

ticles using theory employed either individual- or interpersonal-level theories. Only one-quarter used community-based or multi-level theories such as the Socio-Ecological and Precede-Proceed models. The authors note that "the relative absence of applied community-level theory in the literature is surprising" (Painter et al. 2008). Our own study uses the Precede-Proceed model (DePue et al. 2010), and in a review article Kevin Cassel used the social-ecological model as a framework to understand obesogenic factors among Samoan populations (Cassel 2010).

Anthropology distinguishes between emic and etic approaches to culture, wherein the former seeks to understand categories of thought and behavior from within the cultural participants' point of view and the latter from a scientific or external perspective, allowing understanding of social and cultural structures that an insider might not see (Barrett 1984). These terms and perspectives are, however, not common in behavioral medicine. When, in behavioral medicine, interventions target barriers and facilitators to good health behavior or to health behavior change, those behaviors are being approached from what an anthropologist would term an etic perspective. Thus in Samoa, traditional attitudes about body size, inactivity in older adults, and frequent food-rich cultural events could be understood, as I initially saw them, as barriers to health and among the causes of obesity and its related diseases. But from an emic perspective these very same behaviors provide fulfilling opportunities to create and maintain social relationships in a culturally appropriate way—which in turn promotes well-being and health. Clearly we need both perspectives, and truly translational research cannot proceed without them. Anthropologists are particularly well placed to provide insights needed to balance cultural and evidence-based perspectives.

Anthropological Contributions to Culturally Salient Diabetes Care

In 2006 Mariana Leal Ferreira and Gretchen Chesley Lang edited a volume dedicated to community responses to the high prevalence rates of diabetes in many indigenous peoples (Ferreira and Lang 2006). In that volume, Dennis Wiedman considers the specific contributions of medical anthropologists to diabetes research, noting they have been researching, publishing and giving conference presentations on diabetes since the 1970s, and that native communities in Canada, the United States, and the Pacific have received particular attention (Weidman 2006). Anthropologists have argued that diabetes and other noncommunicable illnesses are diseases of civilization because of their strong association with modernization and the transition to processed food (c.f. Brewis 2010; Ferreira and Lang 2006; McGarvey and Baker 1979; McGarvey 1991, 2001; Weidman 2006).

Wiedman notes that because the breadth of the anthropological perspective incorporates everything from genetics to system-wide structures, it is well suited

to understanding how much the environment and culture contribute to human development. He suggests four specific areas to which anthropological contributions are particularly appropriate: (1) providing groups and leaders with relevant knowledge of environmental and cultural dynamics, (2) influencing healthy food choices within communities, (3) enhancing activity levels with exercise facilities and transportation system design, and (4) influencing health and food policies (Weidman 2006). In this chapter I have argued that there is another place where an anthropological perspective specifically, and a social science perspective more broadly, is particularly needed: the design and implementation of translational behavioral research and the development of theories in behavioral medicine that incorporate culture in a way that respects sociocentric dynamics around health.

Ways Forward: Anthropology and Cultural Models of Diabetes Care

Many anthropologists have identified specific cultural models of diabetes. Rebecca Hagey and Linda Garro each worked in Canada with the Anishinaabe/Ojibway, Chippewa and Cree first nations (Garro 1995; Hagey 1984, 1989). They identified different cultural models of illness and native explanations essential for understanding diabetes, including that it is a form of sickness unknown prior to European contact, an observation that resonates with the comments of participants in our project. Their work incorporated appropriate cultural metaphors and used relevant means of communication, including dancing, drumming and ceremonies, in diabetes intervention. Many other anthropologists have worked within specific communities and the health care setting to ensure the delivery of culturally appropriate medical care (Ferzacca 2000; Hunt et al. 1998; Hunt and Arar 2001). They have documented the use of allopathic and traditional medicine (Hunt et al. 2000) and the effects of stress and acculturation (Dressler et al. 1996; Scheder 2006[1988]), they have identified local understandings of care provision within the context of a demand-sharing economy (Dussart 2009), and they have influenced policy development and intervention design (Ritenbaugh et al. 2003).

These anthropologically informed projects, along with our diabetes intervention in American Samoa, illustrate how to effectively incorporate local or native perspectives and knowledge. But they have not yet fully influenced the theories of health behavior change and behavioral medicine, which continue to focus heavily on individual self-care and individual behavior change rather than on culture, community, and environment. To be fair, there are such theories as the Social Ecological Model and the Precede-Proceed approach that focus on the individual in the culture and environment. But as I discovered in the Diabetes Care in American Samoa project, we need to go beyond these models to fully connect to collectivistic cultures (see Rosen et al, forthcoming).

Recently there has been an encouraging increase in efforts to include culturally relevant perspectives into behavioral theory and interventions. In 2009 the journal *Health Education and Behavior* published an entire special issue on behavioral theory and culture. Two perspectives may be particularly relevant for future research that incorporates culturally informed theory development and intervention design, especially among Polynesian populations: community-based participatory research (also called community engaged scholarship), and research that incorporates social network theory. Our own work has recently begun to inquire into the perspectives of participants, providers and staff about self-management support used in the diabetes care in American Samoa intervention. These perspectives will increase the relevance of translational behavioral research.

Where health is communal, interventions predicated on individual self-care may fail to help. To view culturally informed behaviors as a barrier or facilitator of self-care misses the very point of those behaviors and the motivations that lead people to continue them. Until we can access those behaviors from the emic perspective of the people who engage in them, we cannot hope to alter them or find culturally appropriate solutions to them. Anthropologists and other social scientists should address the absence of relevant, community-level, even community-specific, theories so we create behavioral interventions that are not just translated to new environments, but effectively created for them.

Notes

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