

## NOTES AND COMMENTS

### TIME AND BIOGRAPHY IN DIABETIC EXPERIENCE\*

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*This paper offers a preliminary analysis of temporality in the lives of diabetics. It is argued that time unites the various aspects of diabetic experience, including the disease itself, and the social, emotional, institutional, and technological arenas of that experience. A depiction of diabetic experience is rendered by focusing on family life, time in the individuals' sense of being, and biographical time. It is concluded that diabetes transforms time for the person and for patterns of group life.*

This paper is an exploratory inquiry into how time is experienced by people who have diabetes. The substantive phase of my inquiry seeks to depict the arenas and sets of relations in which time is transformed by virtue of diabetes; the analytical phase, which is suggestive of several conceptual distinctions, seeks to account for the nature of temporality as a diabetic phenomenon. My central argument is that temporal processes are at the very heart of the diabetic experience, that those processes unite the physiological, emotional, social, interpersonal, technological, organizational, institutional, and personal

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arenas in which diabetic experience is expressed and various academic disciplines have claimed each process as the substance of that experience. In selecting temporality as the unifying dimension, I seek further (Maines, 1982; 1983) the ontological inseparability of subject and object, person and society, which characterizes pragmatism and interactionist sociology and anthropology (Mead, 1929; Wirth, 1939; Geertz, 1973).

#### *Theoretical Consideration*

In one way or another, the analysis of time by social scientists and physicists alike have been based on a refutation of the Newtonian position of the exogenous nature of time. Newton regarded time as ontologically prior to consciousness and thus not related to perception. Einstein departed from the Newtonian emphasis on mechanics by stressing that the basic data of physics were in energy rather than matter, and accordingly, Einstein argued that time is dependent upon frames of reference, levels of analysis, and the perspective of the observer. This view also challenged the temporal ontologies of early social theorists such as Comte, Spencer, and even Marx, who depicted time as incremental and linear—the past leads to the present which leads to the future (Hendricks, 1982).

The work of Augustine, Bergson, and Husserl and, though differentially stressed, that of Mannheim, Sorokin, and Gurvich is more consistent with the Einsteinian view in its emphasis on time as a constitutive element of comprehending, experiencing individuals. Generally, Bergson saw the reality of time as an inner experience; Husserl located time in consciousness and memory; Merleau-Ponty located time in the relations between fused “internal/external” events; Mead located all reality in the specious present, and more precisely in the emergent event (Denzin, 1982; 1983; Maines et al., 1983). While there are significant variations between these scholars’ views and those of Durkheim, Mannheim, Halbwachs, and the like, as well as the more contemporary versions of Moore, Anderson, and Zerubavel, I wish to focus on the *commonality* of time<sup>1</sup> as an inherently social phenomenon which is constructed by persons, objectified and reified as an aspect of social structure, and experienced as a phase of individual processes of attending and comprehending.

It is through that commonality which I seek to understand and depict the diabetic experience. In particular, I focus on temporality in the diabetic experience as lived time, and I search for that lived time in how diabetes transforms personal and joint experiences of those who have diabetes.

#### *Diabetes and its Symptoms as Temporality*

In a fundamental sense, diabetes itself is a temporally-defined disease. Whether in the case of juvenile or adult onset, it consists of the pancreas producing too little insulin to metabolize the glucose in the body (Skyler and Cahill, 1981). This condition results in imbalances in the amount of insulin (which functions to open the cells so that they can utilize and store sugar) and sugars in the body *at any given point in time*. Excess insulin can lead to hypoglycemia (insulin reaction) and excess sugar can lead to hyperglycemia (diabetic coma). A range of symptoms accompany these two extremes, and diabetes can lead to many severe complications including blindness, gangrene, impotency, birth defective children, heart problems, kidney failure, and general nerve damage. As a disease, however, diabetes is a complex biochemical and physiological *process*, and its management seeks to stabilize the insulin/sugar ratios. Both can be high or both can be low, and thus it is the phasing through time of insulin and sugar content which is critical.

In this sense, there is very much of an inseparability of the physical nature of the disease, much of which is out of the diabetics’ awareness, and the symptoms of insulin/sugar phasing, which are very much *in* their awareness. Pale and moist skin, nervous and irritable behavior, rapid breathing, a moist and numb tongue, hunger, and headaches symptomize hypoglycemia; dry skin, drowsiness, deep labored breathing, vomiting, a dry tongue, thirst, and abdominal pain symptomize hyperglycemia. These symptoms can occur in sequence or simultaneously, but aside from the person losing consciousness, they are the primary link between the persons’ lived experience and the bio-physiological functioning of the body.

These symptoms are clues which the person uses to interpret not only the current state of bodily functioning but what

it was an hour ago and what it is likely to be an hour from now. They can take on an objectified form through various tests which are self-administered by the diabetic. Periodic blood or urine tests, ranging from one to six times daily depending on the person, give readings on sugar which has spilled over into the bloodstream or urine. Urine tests provide an estimate as of about an hour ago, and thus the person can never know what his or her body is like NOW. Blood tests, through the use of chem strips, provide a current reading. Clinical assay analyses, called glyco-hemoglobin tests, measure sugar which has attached itself to red blood cells, and they measure sugar balance over a two-three month period of time. These tests, while a necessary part of the diabetic's life, are only technological ways of representing the person's physiology and objectifying those symptoms which might exist.

The other critical temporal aspects of diabetes are that life expectancy is reduced by one-third and, because diabetes is not curable, the process of interpreting symptoms goes on twenty four hours a day for the person's entire life (Strauss and Glazer, 1975). Even if symptoms are not manifested in the present, the person must maintain a level of awareness that they might manifest themselves in the future. A watchfulness is thus mandated by the disease, and self-awareness of the body becomes heightened.

#### *Arenas of Temporality in Diabetic Life*

The temporality of diabetic life moves out from the experience of symptoms into the arenas of social relations which contain their own non-diabetically-defined temporality. In the process of that outward movement, the schedules and routines of everyday life become modified. This transformational process stems directly from the regimens which constitute the basis of diabetic self-management. That management pertains to dietary restrictions (e.g., a 2200 calorie/day with 50% carbohydrates distributed in given proportions through three meals and three snacks per day), self-administered blood or urine tests 3-6 times per day, self-administered insulin injections 2-3 times per day, a regulated amount of exercise which is

coordinated with food and insulin intake, and daily foot inspections. Consider how this kind of regimen, which itself is a schedule of activities and concerns, re-defines the temporal organization of family life.

The family, especially for diabetic children, is part and parcel of the medical situation, because the diabetic condition permeates to one degree or another most if not all aspects of family life. The symptoms, regimens, and crises of diabetes lead to temporal disruption and re-definition and therefore to the imperative of time management. In the case of adolescent diabetes, that time management usually falls directly on the shoulders of the parents, particularly the mother (Benoiel, 1975). Parents are responsible for fitting the treatment regimen into the ongoing schedules of activities of the family. One common aspect of this arises from the necessity of timing insulin and food ingestion and the pressured schedule that must be followed to avoid complications once insulin has been taken. Each day begins at the same time with a urine or blood test followed by an insulin injection to be followed by a specially prepared breakfast within a half hour of the injection. This must be done in the context of other household activities such as parents having to get ready for work, getting other children off to school, and so on. Early mornings can be hectic even in the most well-organized families, but the addition of diabetic procedures results in the re-alignment of activities and the emergence of problematic situations (DeBussey, 1970).

Food control, which is a major part of family timetables, also is rendered problematic by the diabetes of a family member. The diabetic regimen dictates what kinds of food in what amounts must be eaten when, and adhering to that regimen often is accompanied by ambiguity and tension. Families with an irregular eating schedule, for instance, must decide whether to feed an adolescent alone or change the dinner hour to an earlier time. The complex problem of food control and scheduling transforms the meaning of food for the diabetic. Food not only means nourishment to people but warmth, ritual, and membership (Wagner, 1966). The diabetic soon becomes an

outsider to these meanings, as food becomes part of the "treatment." Meal scheduling thus often has the effect of differentiating the diabetic from other family members.

The re-organization of the meaning of time for the family is especially apparent during crisis occasions. For parents, the full meaning of having a diabetic child comes with the recognition that responsibility is a 24-hour a day task which includes the daily monitoring of symptoms. In the course of assimilating these new responsibilities, mothers in particular are reminded of how time-bound their lives become, and they frequently describe themselves as being tied-down.

The appearance of hypoglycemic reactions is one of the first signs that monitoring the child is not a routine matter. That reminder is especially potent when these reactions occur at night, as they usually do. With the passage of time, parents become familiar with warning signs, but they also may become overly sensitive to symptom cues. Irritability, for instance, may indicate the onset of hypoglycemia or it may merely be associated with having had a bad day at school. Such ambiguity can lead to delays in seeking medical help or unnecessary assistance. In the course of it all, family members may become extremely watchful and the child may become overly fearful and dependent (Quint, 1970).

Such temporal adaptation has an emergent quality to it, and family organization can become fragile. Ongoing transitions occur as diabetic children become older and as individual and family lifestyles change. Free time can be impinged upon, traveling is problematic, and peer relations become altered by virtue of the diabetic condition. For persons of any age, the management of diabetes is far from an individual process, because it enters directly into the joint lines of conduct which constitute various arenas of participation. The temporal properties of the disease itself and its symptoms thus become an aspect of the temporality of other peoples' lives and the embedded relations through which those lives are carried out.

#### *Variations in Lived Diabetic Time*

I now turn away from the question of the temporal coordination and re-organization of activities which are mobilized

by a participants' diabetes and return to the question of the nature of the diabetic experience. In particular, I seek some understanding of the nature and experience of lived diabetic time.

It is common for us to think of time as flowing past a person, receding either into the past or fading into some other temporal destination. Invariably, we rely on the standards of clocks or calendars when faced with the issue of measuring that flowing temporal process. Even though the meaning of clock or calendar time depends on relational events, it glosses over the dynamic nature of time as lived experience. Halbwachs, Husserl, Mead and others have emphasized the importance of memory and intention in the structuring of temporality. They force the processes of reflexivity and attention into the analysis of time, and through them we may be able to glimpse the individual's extended sense of duration and the speciousness of time. The awareness of self in that duration always occurs in a present, as Mead so clearly described, in which pasts and futures fold back into one another, existing in part as pure fiction and in part as unalterable fact, and where successive presents are not merely sequenced by sequentially situated (Maines, et al., 1983).

It is important to attempt to grasp that experience as it occurs in the lives of diabetics. In that attempt, I offer two categories of information from diabetics I have studied and have come to know during the past year. The categories pertain to the sense of *duration and being*, on the one hand, and the sense of *duration and biography* on the other. I treat these as categories because being and biography overlap and are really only aspects of lived experience. Some of my respondents have made that distinction for me, and so it is important to try to apprehend that differentiation of experience.

Lived diabetic times as an *experience of being* is compressed time. I asked a 31-year-old diabetic woman about time, and she responded:

I'm very, very conscious of time. That becomes really irritating to me. I would like to let go and not worry about whether it's

9 a.m. or 12 noon or that it's 9 a.m. and I've got three hours until 12 noon and I've got to be somewhere in three hours so that I can eat. Like, if you go out hiking with the Sierra Club or something, you have to have something in your backpack or you have to be somewhere where you can stop and eat. And there have been times when I'm grabbing things out of my pack on the "el" or in between moving from one place to another. But it's like I have got to make that time. There's no way of avoiding eating or avoiding doing those things when they really should be done, because I will suffer if I don't do it when it's supposed to be done.

Another respondent similarly stated:

It seems like sometimes I think about this stuff, and it seems like I think about it twenty-four hours a day. I mean, if I go away for a weekend, I have to think of whether there's going to be a restaurant there. I have to think of what things I have to bring with me in case I can't find a restaurant. I have to plan the whole weekend ahead of time to make sure that I have the food or I have whatever I need at certain times of the day. Maybe I'm overcompensating, but I don't think so, because there have been times when I've gotten stuck in situations where the stuff wasn't readily available—maybe we didn't make it to a restaurant exactly at noon and we were on the road somewhere and we thought there was going to be one somewhere but there isn't going to be one for 16 miles, the sign says. At least in that situation, I have my peanut butter crackers and my apple and my couple of celery sticks or whatever in case of emergency. But I thought about that two days ago—that is, what I have to have this weekend in case this should happen. And, I don't like doing it. I mean, I would rather go somewhere and not have to worry about things, but I have to be because that's the nature of my condition.

Compressed diabetic time entails the "making of time," which is a kind of experiential paradox. At the heart of felt compressed time is the process of attempting to create time

normalcy. The compression of time is time falling in on itself, while the creation of time is expansive—time moving away from itself. The future is drawn *vividly* into the present, compressing diabetic regularity. The durations *in* the experience of being magnify what it is to be human, to deal with oneself as an organism, and to deal with the self as an agent and object of control.

That sense of being as it is experienced in situations of high blood sugar reveals other aspects of lived diabetic time. One of my respondents was describing her job with the Social Security Administration and how job stress affects her blood sugar levels. I asked her to "take a snapshot" of those experiences and tell me how they feel.

The feeling is being real wound up—of feeling like I don't have any kind of release. And that's hard to deal with because I have to back up and I have to say OK—you know, I count to ten, and wind down a bit. But sometimes that's real hard to do at work, when I've got a number of cases that I've done and I'm getting errors back on them, and then I get one more and that's kind of icing on the cake. Sometimes it is real hard to back down, and it takes awhile to get the blood sugar down. Other times, when I'm able to and I can step back and breathe a little bit, then I can do something about it emotionally in terms of relaxing. But there are times when I have a real hard time doing that. But I feel real wound up, like not able to loosen up, and that's a real uncomfortable feeling.

She "backs up" and "steps back and breathes a little" during these moments of being wound up. The emotion and the body are inseparable in her experience of herself (Cf. Denzin, 1983), and she describes a self-therapy which involves moving backwards, away from the moment of inseparability, to an emotionally relaxed moment of greater separability. Temporally, she seeks to regain a past before she was "wound up real tight," but that past rests in the future. She has a difficult time doing this, she says. That past is recoverable only in her memory and

in her attending to it as a past, but her being wound up fights against her desire to reproduce it in the future.

My emphasis here has been on the moment of experience and how duration becomes compressed in that experience. In these moments, it is almost as if time cannot escape the lived diabetic experience. Pasts and futures are almost too close to one another in the present to constitute meaningful distinctions. Those distinctions become clearer, however, when considering the second category of information I mentioned. I now turn to the question of *biography and duration* in lived diabetic time. I am concerned here with how actualities of the past have actuality in the present and how futures become mechanisms of shaping presents into what Mead (1929) called emergent events. The relevance of that process for diabetics can be shown by considering aspects of the biographies of two men in their early 30s, whom I call Bill and Jim.

Bill grew up in what he called a "crazy house"—his family. His father was an alcoholic and was very belligerent towards everyone. He bullied his family and periodically had to be "locked up." All Bill's brothers and sisters now have left home as a result, and his mother is seeking a divorce. When Bill was growing up, he avoided his family and its stress and instability. He would come home from school, get his bicycle, and stay away from his house as much as possible. When he was diagnosed as a diabetic, he was made to feel like he did not have long to live, and he was treated as a cripple. "You're a goner now," his mother had said to him. His grandmother had been a long term non-compliant diabetic, and had her leg amputated when Bill was ten years old. That was an instance of what Bill described as a general "I don't care" attitude of the entire family. "I've still got that attitude," he said. "I don't think about the future." It is that attitude that Bill actively lives his fatalism.

Jim's father was diagnosed as a diabetic when Jim was seven years old, and he and his two sisters after that were served the same diabetic diet his mother served to his father. Jim resented the "little bit of this and little bit of that" meals. He had his first glucose tolerance test when he was eleven, and was found to be borderline diabetic. The meals he so resented as an

adolescent probably postponed his onset. His father increasingly became absorbed in self-pity and his illness to the point that there was little time or energy to spend with Jim. Jim resented that as well, and their relationship deteriorated to the point of fistfights and Jim's alienation from his family. Jim graduated at the top of his high school class and was admitted to Northwestern University on an academic scholarship. "Then I was free," he said. "I was into instant gratification to the max—bound and determined to make up for the times when I could have only two cookies. You know, I'd sit down and have two pounds of Oreos and a half a gallon of milk and just pig out." He also became heavily involved in alcohol and drugs, soon lost his scholarship, and dropped out of school. Eventually, he joined Alcoholics Anonymous and Narcotics Anonymous, but acquired the lifestyle of working excessively—100 hours a week—which itself was destructive. "I bought a house but my house wasn't getting any attention," Jim stated. "And I wasn't getting any attention. Nothing was but my work and my bank account. I know things weren't right. I could be driving home and all of a sudden have to go to the bathroom and not be able to make it." During his three week hospitalization after diagnosis, he inquired about support groups for diabetics and joined one for young adults. His conscientious approach to his diabetes is referenced by his now deceased father's approach: "I don't want to deal with my diabetes the way my father did. I don't want to kill myself that way." Jim also does not want to oppress others with his diabetes the way his father oppressed Jim with his, and thus he seeks every means to achieve stability in his personal life. He compulsively seeks that stability.

I would stress two points relevant to these brief depictions. First, the concept of "compliance" with the diabetic regimen, as it is found in the medical and psychosocial literature, tends very much to ignore biographies (e.g., Lowe and Lutzker, 1979). It is as if presents are cut off from their pasts and futures. Yet, Bill's biography as a meaning of his present has everything to do with compliance—or better, his non-compliance, since Bill's diabetes is chronically out of control. His blood sugar levels are elevated, he has red blotches on his face and

neck from past and present boils, he is very underweight, and he has tingling in his legs and eyes which indicate nerve damage onset. He actively carries a meaning of his biography into the decisions he makes about his diabetic management. His biography is a kind of perpetual incipient act—an attitude—which he accepts as a life condition. In that attitude is a bifurcation of his ongoing diabetic experience—a simultaneous acceptance of his diabetes and his denial of it. That experience and his images of his past reproduce the “I don’t care” attitude as a context of future experience.

Jim’s biography likewise is very much part of his compliance. Only his compliance takes a different form, which I would contend stems from a different use value of his past. Jim seeks to utilize every bit of knowledge and available resource to maintain normal blood sugar levels and to come as close as possible to normalcy in his life. That utilization sharply differentiates Jim from the past of his father, and, furthermore, Jim actively seeks to create and maintain that differentiation. His biography is not an incipient act in the sense that Bill’s is, but a similar bifurcation of his diabetic experience exists. Through actively differentiating his diabetes from his father’s and his childhood experience of his father’s diabetes, Jim must incorporate them into his ongoing experience.

The second point relevant to these biographies pertains to the nature of extended time. Both Jim and Bill realize the probability of their having a reduced life span. But Jim envisions his future, and he fights against what might be called a diabetic future—one of inevitable complications. “I’m not going to be a walking self-fulfilling prophecy,” Jim says. He pulls the diabetic future into his awareness and attempts to forestall or even neutralize it by fighting against his father’s former future. Time is compressed in Jim’s experience; time is not compressed in Bill’s. For Bill, his future is symbolized and defined by that of his grandmother’s. There was never much of a point in thinking of the future in Bill’s biography—or in those of his family. Thus, what happens, happens. The future is amorphous and translucent; time is ambiguous, lacking the sharp edges of time consciousness; and the self seems to float on top of the diabetic experience.

### Concluding Remarks

In this brief analysis, I have sought a way to depict how temporality is experienced by diabetics and the nature of time in the phenomenon of diabetes. My inquiry began with the contention that subject and object, person and society are inseparable, and that they only represent different aspects of the same thing. I have argued that temporality unites the various aspects of diabetes, including the physiological nature of the disease, its symptoms, the treatment regimens, participation in group life, and human experience. I find a close correspondence among those aspects of diabetic life, which I have tried to depict as lived diabetic experience. It is important to understand such ontologies for what they can tell us about human temporality, about diabetes, and also about what health professionals ought to have as their stock of knowledge in their attempts to facilitate diabetic self-management.

### FOOTNOTE

1. Primary material pertaining to these views can be found in: Bergson (1965), Durkheim (1915), Husserl (1964), Augustine (1953), Mannheim (1952), Halbwachs (1950), Sorokin (1964), Moore (1963), Zerubavel (1979), and Anderson (1974). Discussions of various approaches to temporality can be found in Hendricks (1982). Bergson’s conception of *durée* and Mead’s (1929) treatment of the specious present are especially important for the views I express in this paper. Bergson specifically recognized the subjective nature of the experience of time as distinct from the mechanical notion of clock time. For Bergson, the moment has *durée*. Experience is inherently temporal; it has duration. Firm lines between past, present, and future cannot be drawn, since they merge together in an ongoing flow of moving inner phenomenological time. An indirect treatment of *durée* in terms of standard sociological concerns can be found in Maines et al. (1983).

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