

9 The Experience of Temporality by a Group of Asian and Caucasian Diabetic Patients

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Abstract

This contentious paper aims to explore the experience of time by individuals who have been diagnosed with diabetes mellitus. It further argues that the temporal processes form central to the diabetic experience and it proceeds to depict the arenas in which time is transformed by virtue of diabetes. Finally, it is proposed that understanding the person as a whole being is necessary if self-management of diabetes is to be successful.

Introduction

The global pandemic state of diabetes mellitus is sombre with no signs of abating. It has been predicted that the adult diabetic population will peak to 300 million world-wide (King et al., 1998). In UK, this condition will rise from the current estimate of between 1.3 million and 1.4 million (Diabetes UK, 2000) to 3 million by the year 2010 (Moore, 2000).

Since this condition is incurable, self-care management becomes the responsibility of the sufferer. The life of the diabetic individual revolves around a temporal regularity. For example, in type 1 diabetes, meals, exercise and blood glucose monitoring are planned and carried out to match those times when insulin levels are expected to drop or peak. Although self-care is an integral facet of diabetes management, this paper argues that the impact of temporality on the life of the diabetic person and close family members cannot be ignored. It is therefore the aim of this paper to offer a contentious analysis of temporality as experienced by a group of Asian and Caucasian diabetics.

Theoretical Consideration

The Western conceptualisation of time is a complex, interweaving of scientific analysis, myth and metaphor. The quote from St. Augustine is relevant here for it provides a clue as to why philosophers and social scientists are constantly

perplexed and seduced by the question of time. In his book, *Confession*, St. Augustine lamented 'o what, then is time? If no one asketh me, I know: If I wish to explain it to one that asketh, I know not ...' (1961, 264). This implies that there is something known as time in the form of a sensation about the way the world is to us. Essentially, it is an experiential knowing. Others, for example Einstein (1949) departing from Newton's concept of objective time, added that time is dependent upon frames of reference, levels of analysis and the observer's perspectives. Einstein's proposition was consistent with the works of Sorokin (1943), Mainheim (1952), Gurvitch (1964), Husserl (1964) and Bergson (1965), who stated that time is something that the individual understands and experiences. These views challenged the propositions of other scholars who depicted time as incremental and linear: that the past leads to the present which leads to the future (Hendricks, 1982).

Perception of Time in Sickness and in Health

People experience time with great variations (Jantsch, 1980). The task we undertake can affect our temporal perception. For example, 'time flies' when we are involved in projects we enjoy but it slows down to 'a snail's pace' when the job is ponderous and difficult. In exploring how diseases bring one 'close to the bone' of the soul's needs, Bolen (1996) discussed the two Greek words for time, namely *chronos* and *kairos*. He suggests that our images of time during healthy and normal circumstances are located in *chronos*, whereby human actions are bound by the mechanical units of the clock time as we go through our daily schedule of chores and appointments. Time is hence quantified (Rämö, 1999). However, when an individual is diagnosed with a chronic condition, like diabetes mellitus, or impending death, then s/he may find that their sense of time, the passage of days and their views of the future are altered. In this context known as *kairos*, individuals become released from the bounds of the clock in an attempt to experience quality time. As Bolen (1996, 86-88) asserted that 'there are high achievers and caretakers who never questioned whether they were doing what they really wanted to be doing with their lives, until a life-threatening illness stopped them in their tracks'. This is the point when one's commitment to *chronos* is lessened and instead, *kairos* is sought where people spend time in soul satisfying and nourishing activities. Here, as Bolen added, rewarding activities help individuals to lose their sense of time passing as they spend time with those they love, or by working in the garden or going for walks. In the context of diabetes, people often see time both in *chronos* and *kairos*. As Amis (1998) suggested, for them, time is running backward as well as forward, with life spreading on a landscape. Those affected may begin to think of where they have been and where they

came from, of their families and relationships, and of what came before and what comes after.

Methodology

This paper forms part of a recently completed PhD research project (Meetoo, 2002) which primarily explored the notion of non-compliance and diabetes self-care activities of 25 Asian and 24 Caucasian patients diagnosed with either type 1 or type 2 diabetes. Following approval from the Local Research Ethics Committee, qualitative data generated from health diaries and semi-structured interviews also examined the participants' experience of temporality during their self-care trajectory.

Analysis

The analysis began by examining the relationship between temporality and diabetes. It argued that in many ways diabetes is a temporally defined condition characterised by the pancreas secreting insufficient insulin to metabolise glucose in the body (Skyler and Cahill, 1981; McClinnic, 1985). Such imbalances in the insulin/sugar ratios can therefore occur at any given point in time. It is also well known that extreme level of insulin or sugar can lead to hypoglycaemia or hyperglycaemia respectively (Fox and Pickering, 1995; Dunning, 2003), detected by a wide range of symptoms. Further, diabetes can lead to early life-threatening complications (Vijan and Hayward, 2003). Since diabetes management aims to stabilise the insulin/sugar ratios (both of which can be high or low) it is thus the phasing through time of the insulin and sugar contents, which becomes critical. Further, analysis suggested that the physical nature of the disease, (much of which is not within the person's awareness) is inseparable from the symptoms of insulin/sugar phasing, (which is within the person's awareness). Consequently when the diabetic person is experiencing hypoglycaemia or hyperglycaemia, the symptoms can occur in sequence or simultaneously. Apart from losing consciousness, these symptoms are, therefore, the only primary link between the person's lived experience and the bio-physiological functioning of the body.

Diabetic symptoms are therefore clues used by the individual to interpret not only the current functioning of the body but also what the body was an hour ago and its likely state in an hour from NOW. Technological tests act as objective indicators of glucose levels spilled in the blood stream or urine. Except for HbA1c measuring the blood glucose trends over the preceding three months, the other blood test undertaken by the patient himself/herself as part of

diabetes self-care management, provides a current (NOW) reading. Although infrequently performed, urine test estimates of how the body was an hour ago but not how it is NOW.

Another temporal feature of diabetes is that life expectancy is reduced by one third (Donnelly et al., 2000). Further, since this condition is incurable, it means that symptom interpretation occurs on a daily basis and it continues throughout the person's entire life. Even if the symptoms have not manifested themselves at the present time (NOW) there is no guarantee that they will not manifest themselves in the future. The diabetic person is vigilant at all times and self-awareness of the body too becomes heightened at all times. The following two excerpts from the health diaries indicate how vigilant the diabetic participants were:

Woke up this morning ... I have noticed a small crack on the heel of my right foot. This needs attention so first off to bath, clean and check feet and toes to make sure everything else is ok. (Jean)

9.12 am checked feet after shower. Big toes have suddenly become sore Had a lot of trouble last night and this morning I woke up with pain in my toes and legs and calves ... (Martha)

Temporality, Diabetes and Social Relations

From the temporal experience of symptoms, data explored the impact of diabetes on social relations. Analysis suggested that the cyclical process involved in managing diabetes can trigger temporal disruptions in the family life. This is particularly evident when considering the daily diabetes self-care activities: the need for dietary modification, which becomes a treatment and not a social family event. Consequently, the type, amount and time when food can be eaten have to be reviewed. A number of blood or urine tests are measured at regular time intervals. Self-administration of insulin injections and its adjustments at different times of the day becomes a necessity. Recommended exercises co-ordinated with dietary intake, are performed on a daily basis. Finally regular foot care needs to be undertaken to avoid related complications. Often this regimen corresponds with other timely household activities, for example, preparing meals for other non-diabetic family members. Data entered in the health diaries pointed to family tensions:

Had one chappati with curry which was tasteless because wife cooks separately for me ... (the next day) had some food - salad sandwich and tea. I was angry with my wife because she didn't give me curry and rice ... we didn't speak ... went to town window shopping. (Anif)

Ali expressed his family organisation thus:

We often have arguments in my house. Had an argument again with wife and son about food. Went out in a bad mood. I get very moody from time to time. I never used to get angry or moody but I think diabetes has done this to me....

The meaning of time becomes more evident at crisis occasions. For it soon dawns that having a diabetic family member is a twenty-four hour responsibility. Monitoring for hypoglycaemic reactions usually occurring at night-time is a reminder of this fact. Further there is a tendency for the other partner to become overly sensitive to symptom recognition. For example, irritability, a symptom of hypoglycaemia can also be associated with the diabetic partner having had a bad day at work.

Non-diabetic family members inevitably become involved in the self-care management of the diabetic person. In coming to terms with the new and/or added responsibilities, they are mindful of how time-bound their lives become. There is no free time for free time is often impinged upon. Thus, family organisation can become fragile.

Temporal Variations in Diabetic Lives

Another aspect of data analysis examined how duration and being (lived time) and duration and biography influence diabetic lives. The former refers to the diabetic life as it is unfolding now. Here the individual attempts to create normalcy through careful management of lived time thereby establishing ongoing regularity of self-care. In so doing, the future is drawn in to compressed time of the present. The latter, however, refers to the impact of expressed views and attitude of significant others in the life of the diabetic person. Here, the analytical aim was to understand how the experience of time flowed through the participants' lives. The next two extracts exemplify the first phenomenon. During her interview, Adele, expressed her view of time thus:

Although I'm conscious of time I don't do anything that reminds me of the fact that I have diabetes. I see myself as normal. However, in caring for my illness [diabetes] I look at my day in terms of when I'm going to take tablets for my Addison's disease, when I'm going to take my injections For example, I know that by 7.00 am I need to have eaten my slice of bread or my two slices of bread and given myself an injection after that. I know by 1.00 pm I need to be eating as well. By 7.00 pm I should have eaten something and certainly before I go to bed at 11.00 pm I need to check that everything's ok before I do my last injection and make adjustments if it's not ... (Adele)

In another interview, Mary discussed the reasons for her temporal adherence:

... so although I'm a diabetic I still see myself as being normal. To behave normally means that I've got to be careful about what I'm doing at all times. I've got to plan my long journeys and take snacks for emergencies like normal people would do. I couldn't for example set off one day and say, right we'll just go out today and take a drive out and see where we end up and eat when we feel like eat. Normally people don't do that. I would have to be close to somewhere where I could eat when I'm hungry and on time.

Normalcy can often become disrupted by other events affecting the diabetic experience. Rachel provided a snapshot of such an experience and how it affected her diabetes:

My job as a teacher is very stressful indeed. Not only am I doing my teaching job, I'm also trying to look after the pastoral well being of one third of the school and that means there could be any sort of problem thrown at me during the day, quite often during lesson time ... When I'm stressed I get very wound up, lacking in patience, short tempered It affects my blood sugar and I become prone to hypos. To wind down I would do lots of different things, occasionally if I've got to the point where really I've got to take an hour out, go to the local McDonalds, glass of orange juice and a cup of coffee. I'd just move away, get back in to the land of living and then go back afterwards and then I'd see things in a slightly different way.

The above scenario portrays the flow of time within the participant's coping mechanism during a stressful experience. In dealing with her stress, she undergoes self-therapy by emotionally stepping in to the past to gain a state of calm. She then moves back in to present, which was essentially the future when viewed from the past. In this sense the past, the present and the future become almost indistinguishable.

The second phenomenon, duration and biography, differs from the first. Here data analysis pointed to how the events of the past are linked to the present thereby shaping the future, a state known as the emergent events (Mead, 1929). The relevance of this process was apparent in some of my participants' biographies. During her interview, Emily commented on the efficacy of her support system:

I get very good support from my GP, the doctor (Diabetologist) at the clinic, particularly Susan (DSN) who teaches me how to keep my blood sugar down. My husband is very supportive ... but its nice to know that they (family members) think that much, you know, you've got that support ... so I make it a thing that I've got to comply with the treatment ... even when I've been ill, you know, ... now it's a way of life for me I'm afraid. I look at it this way: I've got it [diabetes]

and I've got to be doing the things I've been told or else there's only me who will suffer. I wouldn't like to go blind or I don't think I would like to lose any limbs.

The views of Karen differed from the above when she said:

When my dad found out that I had it [diabetes] erm, ... he was coming out with stupid remarks. I can't remember what they were now ... he wouldn't talk about it (diabetes) and if I mentioned it ... he would change the subject ... he wasn't supportive. I don't always comply. I don't like blood test because it hurts. My diabetic nurse has told me that I don't have to do it. I smoke no more than 10 cigarettes. They are the cheapest and they are not really strong like B&H ... I let myself down with food and when I go out for meals ... I drink up to one bottle of red wine ... then I will have a pudding ... I find it difficult to find time to exercise or go for a walk ... I don't see my GP or the doctor at the clinic just the nurse (DSN). I'm hoping for a miracle cure

Both biographies are concerned with the notion of compliance. However, a distinction was made. In the former, compliance seems to emerge from past values, belief, support network as well as acceptance of the condition. There is a determination on behalf of the individual to adhere with the diabetic regimen in order to bring about normalcy and to prevent diabetic related complications. The second biography is almost a representation of denial. Although aware of her diagnosis and related complications, lack of family support seems to have impacted in her non-compliant attitude and behaviour to diabetes self-care management. Until such time a 'miracle cure' is discovered, it seems that her approach to self-care will remain unchanged.

Conclusion

In this analysis, I sought to portray the relevance of temporality as experienced by my participants. It was also my contention that subject and object are inseparable, representing the different aspect of the same thing (Merleau-Ponty, 1962). In this context, it is my proposition that temporality unites different aspects of diabetic life. Further, the concept of self-care is far from an individual responsibility because the temporal properties of diabetes and its symptoms inevitably have an impact on the temporality of those who share the lived diabetic experience. My analysis also depicts the importance of incorporating biography when delivering diabetic care, a concept often ignored in a medical or psychosocial encounter. Finally, the importance of understanding ontology and temporality in the context of diabetes cannot be ignored. These two concepts should form part of health carers' stock of knowledge if diabetes self-care management is to be effectively established.

For while each of us lives in our own time, no two persons living at the same time live in the same time.

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