PSYCHOSOCIAL FACTORS IMPACTING ON TREATMENT ADHERENCE IN DIABETES

David Lydon
Senior Sophister, Psychology & English
dlydon@tcd.ie

ABSTRACT
Diabetes is a chronic condition which, if left untreated, can lead to serious health and economic consequences. The current model of medicine, the biomedical model, has been successful in describing diabetes and identifying treatments. However, while the effectiveness of diabetes treatment has been proven in a number of studies, adherence to treatment is extremely low. The author suggests that a biopsychosocial model, with an explanatory focus beyond that of biology, may contribute to our understanding of treatment adherence in diabetes. This article explores ways in which two psychosocial factors – stigma and identity issues – impact on treatment adherence in diabetes.

AN OVERVIEW OF DIABETES
Diabetes is a chronic medical condition characterised by abnormalities in glucose metabolism. There are two major types of diabetes: Type 1, often called insulin-dependent diabetes mellitus, and Type 2, often referred to as non-insulin dependent diabetes mellitus. Type 1 diabetes involves the pancreas losing its ability to produce insulin, resulting in uncontrolled elevations of blood glucose (Peyrot, McMurry, & Kruger, 1999). Insulin production in Type 2 diabetes is initially impaired, but cell tissues become resistant to the action of insulin. In response to the elevation of blood glucose, insulin levels increase and, for a period of time, compensate for insulin resistance. Following a number of years there is eventual damage to the pancreas due to an overworking of cells contained therein (Gonder-Frederick, Cox, & Ritterband, 2002).

In the United States, diabetes is the seventh leading cause of death and the total direct and indirect costs due to diabetes in the United States have been estimated at €102 billion per year (Ciechanowski, Katon,
Russo, & Walker, 2001). The prevalence of diabetes (particularly Type 2 diabetes, which composes 90% of diabetic patients; Nolan, 2006) is on the rise. A study conducted by Shaw, Sicree, and Zimmet (2010) found that the world prevalence of diabetes among adults aged 20 to 79 years by the end of 2010 will be 6.4%, or 285 million adults, and will increase to 7.7%, or 439 million adults, by 2030.

Serious health complications are associated with both Type 1 and Type 2 diabetes including macrovascular damage, which can lead to heart attacks and strokes (Peyrot et al., 1999). Elevated blood glucose can also lead to microvascular damage, often resulting in kidney failure and blindness (Peyrot et al., 1999). In order to avoid such complications, lifelong treatment for diabetes is needed.

The biomedical goal of modern diabetes treatment is to maintain blood glucose levels as near to normal as possible. Results from a study by the Diabetes Control and Complications Trial (DCCT Research Group, 1993), which followed over 1400 individuals with Type 1 diabetes over an average of 6.5 years, provided evidence that this treatment can delay or prevent the development of some of the serious long-term complications of diabetes. Follow-up studies have also found that the benefits of intensive diabetes management demonstrated by the DCCT Research Group continue to significantly delay or prevent such complications (Morales, 2009). Other studies have demonstrated the benefits of maintaining tight blood glucose control in Type 2 diabetes patients (Okhubo et al., 1995).

While the benefits of treatment have been established, there is a low rate of treatment adherence in diabetes which leads to compromised health benefits and economic consequences (Bartels, 2004). DiMatteo (2004) examined treatment non-adherence in a number of diseases reported in studies between 1948 and 1998 and found that treatment adherence in diabetes was one of the lowest of any other disease worldwide. Adherence has been described as “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider” (WHO, 2003, p.3). Adherence, then, involves behavioural factors, an understanding of which requires the recognition of psychological and sociological factors which, as the following section will detail, are beyond the scope of the biomedical model.
THE BIOMEDICAL MODEL OF HEALTH AND ILLNESS

The emergence of the biomedical model

The Enlightenment’s emphasis on rationalism and the scientific method influenced the development of healthcare and led to the emergence of the biomedical model (Barrett et al., 2003). Ideas that set the groundwork for scientific medicine were positivism, reductionism, and the contribution of Descartes.

Descartes stated that the mind “is entirely distinct from the body” (Descartes, 1993, p.19). This mind-body disconnection did not originate with Descartes – such a dualism was present in the work of ancient Greek philosophers such as Hippocrates (Adams, 1939) and Plato (Grosz, 1994) – but it has come to be referred to as Cartesian Dualism. Descartes introduced three important innovations to this dualism which affected the development of healthcare (Sarafino, 2002): he conceived of the body as a machine and described the mechanisms by which action and sensation occurred; he proposed that the mind and the body could communicate through the pineal gland; and believed that the human soul leaves the body at death (Sarafino, 2002). In this regard, the human body, to Descartes, was passive, mere *res extensa* – part of the physical world – with no intelligence or ability to self-control (Leder, 1984). Fascinated by the automatons of his day, which were able to imitate the behaviour of living things, he reconceived the human body as a machine (Leder, 1992). In contrast to the passive and mechanical body, the *res cogitas* – the mind – held the “essence of the self and the divine aspect of the human being” (Leder, 1984, p.29).

Such a conception of dualism led many scholars of this period to regard the body as subject to the laws of mechanical causality like other components of the physical world and, thus, open to scientific experimentation (Leder, 1984). Furthermore, the Roman Catholic Church granted permission for the dissection of the body as the divine aspects of the human were now thought to be separate from the body. However, the corresponding freedom was not granted to the study of mind and behaviour as these areas of study were deemed only suitable for the domain of religion (Engel, 1977). Thus, mind-body dualism was further
delineated through what was deemed an appropriate separation of mind and body into discrete areas of study.

Following Cartesian Dualism, by the 1850s positivism and reductionism were joined to set a new agenda for medicine (Taubers, 2002). Reductionism may be defined as the practice of “analyzing and describing a complex phenomenon...in terms of its simple or fundamental constituents, especially when this is said to provide a sufficient explanation” (Oxford Dictionaries Online, 2010). The Cartesian view of the body as a machine could be considered reductionist as it suggested that all of the functioning of the body could be explained at the level of tissues and bones. With the conception of the body as machine, positivist principles could be applied to the body. Positivism holds that “the highest or only form of knowledge is the description of sensory phenomena” (Blackburn, 2005, p.284). A positivist methodology is linked to the assumption that “all of nature [is] of one piece, and the study of life [is] potentially no different in kind than the study of chemical reactions” (Taubers, 2002, p.182). The ability to apply scientific principles to the body due to the “radically materialistic thinking” that had developed was seen as a great advantage to the clinical sciences (Schepers-Hughes & Lock, 1987, p.9).

The approach of the biomedical model

Following the emergence of the mechanistic view of the human body, a scientific medicine emerged in the nineteenth century. Adhering to positivism and a mechanistic view of the body, this biomedicine was “characterized by scientific observation and raised on pathological anatomy” (Porter, 1999, p.306). The biomedical model attempted to remove subjective perception in favour of rational objectivity and Xavier Bichat’s Anatomie Générale provides an insight into the way in which medicine at the beginning of the nineteenth century dismissed the subjective view of the patient in favour of objective analysis of the body. According to Bichat, taking notes at the patient’s bedside leads to “a confusion of symptoms...a train of incoherent phenomena” and that only when the human body is dissected “this obscurity will...disappear” (Porter, 1999, p.307).
This biomedical approach assumes that all illness has an underlying pathology that may be cured through medical intervention (Morrison & Bennett, 2006). In this way, the model privileges biological explanations at the expense of social, cultural, and biographical explanations (Atkinson, 1988). Indeed, as the biomedical model emerged from the Enlightenment’s emphasis on science and rationalism, explanations of illness other than the biological are excluded from the model as they are “nonmaterial in form and not measurable, subjective and not objective” (Engel, 1996, p.426). This approach led Samuel Taylor Coleridge in a letter to Charles Lloyd in 1796 to say that doctors “are shallow Animals, having always employed their minds about Body and Gut, they imagine that in the whole system of things there is nothing but Gut and Body” (Griggs, 1971, p.256).

THE BIOMEDICAL MODEL AND DIABETES
The biomedical model has been extremely effective at providing an understanding of diabetes. The model has also been successful in identifying treatments for diabetes. However, due to the biomedical model’s explanatory focus, it cannot address behavioural issues impacting on adherence. This can be better understood when the treatment for diabetes is examined.

The maintenance of blood glucose levels involves adherence to medication, a specific diet and exercise regime (Ciechanowski et al., 2001). The monitoring of blood glucose levels, several times a day, through the use of portable blood glucose monitors is also recommended by doctors in order to determine appropriate self-care actions (Peyrot et al., 1999). Thus, the treatment requires behaviour change and the incorporation of monitoring regimes into everyday life, aspects of treatment which the biomedical model cannot address due to its explanatory focus.

George Engel’s 1977 article, entitled “The need for a new medical model: A challenge for biomedicine”, advocated an extension of the biomedical model of health and illness to include psychological and sociological factors that impact on health and illness. Engel (1977) recognized the importance of biomedical knowledge and, as such, proposed a biopsychosocial model which would include psychological and sociological factors without abandoning valuable biomedical knowledge. Engel understood that the biomedical model was reductionist in
“assum[ing] that the language of chemistry and physics will...suffice to explain biological phenomena” (Engel, 1977, p.130). His critique of the biomedical model included the observations that illness results from the interaction of diverse causal factors, that illness is not necessarily identical to a biochemical alteration, that psychological and sociological factors can determine the susceptibility to and the severity of an illness, that the sick role can be adopted in the absence of a biochemical alteration, and that the doctor-patient relationship is not one of observer and observed (Biderman, Yeheskel, & Herman, 2005).

The biopsychosocial model conceives illness as resulting from interacting mechanisms at the “cellular, tissue, organismic, interpersonal, and environmental levels” and must include the “individual, his/her body and his/her surrounding environment” (Fava & Sonino, 2008, p.1). In this way, the model seeks to address many of the limitations of the biomedical model arising from its reductionist conception of illness. The model re-conceptualizes the patient as a human being and values “the patient’s subjective experience as an essential contributor to accurate diagnosis, health outcomes, and humane care” (Borrell-Carrio, Suchman, & Epstein, 2004, p.576).

**DIABETES AND THE BIOPSYCHOSOCIAL MODEL**

A review of the diabetes literature conducted by the author highlighted a number of psychosocial factors, beyond the scope of the biomedical model, which impact on treatment adherence. This literature will be discussed with reference to a biopsychosocial model of health and illness, which has the potential to act as a framework within which to accommodate these psychosocial factors alongside biomedical knowledge. Due to the limited scope of this report, only two of the psychosocial factors that emerged from the study are explored. These are stigma and identity issues. Stigma was chosen as a factor to be explored as it is very common among the population, with some studies reporting the experience of stigma by all participants involved (Buchbinder et al., 2005). Issues of identity which have been relatively neglected in the research are also explored.
PSYCHOSOCIAL FACTORS IMPACTING ON TREATMENT ADHERENCE IN DIABETES

Stigma

Research has found that the experience of stigma is common among diabetics and often leads to treatment non-adherence. All participants in a study on adolescents with Type 1 diabetes based in the United States reported feeling stigmatized due to their diabetes (Buchbinder et al., 2005). The participants in this study were upset due to the reactions of their friends and strangers towards their diabetes. Some of the common social meanings attached to diabetes that lead to stigma include the conceptions that it is an infectious disease (Lin, Anderson, Hagerty, & Lee, 2008) and that it is a self-inflicted disease of individuals who “lack self-control, who eat to excess and are overweight” (Broom & Whittaker, 2004, p.2373). Certain forms of health promotion media have been found to reinforce the view that diabetics are “failing to take proper responsibility for their health” (Broom & Whittaker, 2004, p.2373).

The treatment for diabetes can also lead to stigmatization. A participant in a study involving seven European countries (Vermeire et al., 2007) reported the experience of stigma as a result of the treatment’s dietary requirements. One participant stated that others “make fun of [his] diet, bawling at [him]” (Vermeire et al., 2007, p.30). Additionally, the use of diabetes technology can often exacerbate stigma experienced by diabetics. Although diabetics have the choice of being able to conceal or disclose their diabetic status (Lin et al., 2008), diabetes technology can highlight diabetic status (Balfe & Jackson, 2007) and so lead them to experience stigma.

Diabetes can also be confused with illegal drug use by the general public leading to stigmatisation. A study by Shiu and Wong (2002) found that the general public looked at their insulin-treated Hong Kong diabetic participants with contempt when they self-administered insulin in public places. These participants believed that the public mistook them as intravenous drug users due to the technology they used to self-administer insulin (Shiu, Kwan, & Wong, 2003). Broom and Whittaker (2004) also found this stigma due to the negative connotations which are a result of the injecting involved in insulin-administration even though the new insulin pens resemble a syringe to a lesser degree than before.
Due to such stigmatizing effects of diabetes treatment, adherence to treatment is often more likely when it can be accomplished in private, hidden spaces. For instance, participants in Balfe and Jackson’s (2007) study were more likely to carry diabetes technologies during the day when technologies could be hidden easily due to the tendency to wear more clothes and to carry larger bags than at night. Other individuals have reported that they preferred to administer insulin only while at home (Shiu et al., 2003), while some tried to avoid “other people’s strange eyes” and inject in places such as public toilets (Shiu et al., 2003, p.150). The experience of stigma can also affect the type of technology opted for by the individual diabetes patient. For instance, one individual in Balfe and Jackson’s (2007) study preferred injections over an insulin pump as she felt the pump would look “ugly” when she was going out (p.784). Additionally, 10 out of 12 participants in another study initially refused a change-over to insulin therapy after a recommendation from their doctor due to anxiety about stigma (Kwan, 2001; as cited in Shiu et al., 2003).

Thus, individuals with diabetes often experience stigma, which can be exacerbated by aspects of diabetes treatment including dietary requirements and the use of technologies. This often results in decreased-adherence to treatment or non-adherence in order to avoid stigma. The biomedical model cannot account for psychosocial factors such as stigmatization towards diabetes. The biopsychosocial model, however, due to its consideration of the social environment and the experience of the patient, allows factors such as stigma to be taken into account.

Within a biopsychosocial framework, focus can be drawn from biological to social factors in order to counter the experience of stigma. This can involve education of the general population in order to dispel myths about diabetes that lead to stigmatization. Mass media campaigns that educate the general public on the aetiology and treatment of diabetes may help to dispel negative attitudes towards diabetes and also clarify the differences between diabetics who self-administer insulin and intravenous drug users (Shiu et al., 2003). Secondly, Balfe and Jackson (2007) recommend that physicians talk to individuals using diabetes technology about the stigma they may experience when using their technologies and how best to deal with it. Finally, since health promotion has been found to reinforce negative stereotypes of diabetics (Broom & Whittaker, 2004), the language of media relating to diabetes health promotion and awareness
should remain objective and refrain from perpetuating stereotypes concerning diabetes.

**Identity Issues**

Research on diabetes indicates that identity issues have a significant effect on treatment adherence. The need for identity coherence - the maintenance of personas exemplifying enduring conceptions of oneself (Swann & Bosson, 2008) – and the wish to attain one’s desired identity affect diabetes self-management. Diabetes treatment plays an ambivalent role in identity issues, sometimes preventing individuals from achieving their identity goals - achieving their desired self and participating in activities integral to one’s self-concept (Swann & Bosson, 2008) - and sometimes allowing individuals to attain their goals.

Diabetes treatment involves the adoption of significant changes to lifestyle. The treatment and the illness itself introduce major disruptions to daily routines and activities (Mamykina, Miller, Mynatt, & Greenblatt, 2010). The experience of identity disruption can be anxiety-producing (Mendes & Akinola, 2006) and this may lead individuals to maintain a connection with their habits before they were diagnosed with diabetes in order to maintain a coherent identity between their pre- and post-diabetes perception of themselves (Mamykina et al., 2010). This practice of maintaining a sense of identity between pre- and post-diagnosis behaviours was evident in a study by Mamykina et al. (2010), which investigated the potential of a computer-based health-monitoring technology to help improve diabetes management skills. When the technology was used by individuals who had lived with diabetes for a number of years, the technology was used to record personal stories, many of which were not related to diabetes management. The stories recorded helped the individuals to maintain a consistent sense of self and to create a link between their lives with diabetes and before diagnosis. For example, one participant recorded having eaten fresh, bakery-baked bread as he and his family “usually never buy bread from the store” even though the bakery-baked bread was “a bit heavier on carbs” (Mamykina et al., 2010, p.5). Sticking to the family tradition of eating bakery-baked bread may have conflicted with the participant’s treatment regime but, in the eyes of the participant, it was worth it. The researchers concluded that this behavioural continuity was a way of maintaining a coherent identity. This...
is one example of the way in which identity continuity is maintained and also highlights the way in which identity issues, factors beyond the scope of the biomedical model, can affect treatment adherence.

Other research on diabetes highlights that the maintenance of a desired identity is often more important to the individual with diabetes than adhering to treatment. For example, a participant in a study by Smith, Frost, Albayrak, and Sudhakar (2006) showed the researchers a picture of her new tattoo saying

That was my tattoo...that I wasn’t supposed to get. Cause my doctor didn’t think it’d be a good idea. (p.316)

Another participant who had recently had her nose pierced similarly stated that it was against the wishes of the doctor. For both these individuals, the desire to pursue their desired identity was more important than adhering to the doctor’s recommendations.

The wish to pursue a desired identity which conflicts with the treatment regime for diabetes has been studied at length in the university student population. Students pressure themselves to hold a ‘normal’ identity (Litva, Peggs, & Moon, 2001). Indeed, research on university students with diabetes reflects this with participants in a study involving university students with diabetes desiring to be “normal” (Balfe, 2009). Balfe (2009) suggests this perceived “normality” implies pursuing the same activities as other students and preventing diabetes from affecting their student lives. Indeed, Balfe (2009) found that adherence to diabetes self-care routines became less stringent as students with diabetes participated in ‘normal’ student activities such as staying up late, drinking, and going to clubs.

Other research on identity issues in diabetes found that the extent to which students with diabetes adhered to their treatment regimes depended on the extent to which they accepted diabetes as part of their identities. A participant in a study by Balfe and Jackson (2007) integrated diabetes into her identity in an attempt to become ‘normal’. The participant rebelled against her diabetes when she was younger by not adhering to the regimen at all. When she went to university, she accepted diabetes as part of her identity and regularly brought her testing equipment with her when she went out to drink. Bringing the technology with her, Balfe and
Jackson (2007) suggest, was fuelled by a desire to feel that she was not different to others, that there was nothing wrong with diabetes or diabetes technologies. This demonstrates that accepting diabetes as part of her identity can allow patients to live as close to a ‘normal’ student lifestyle as possible with the least detriment to the diabetes regime.

Indeed, accepting and using the diabetes technology often enabled participants in Balfe and Jackson’s (2007) study to fit their diabetes more easily into their student lifestyles. Technologies allowed participants to manage and control their bodies and participants acknowledged that the more control they felt they had over diabetes, the freer they felt from it (Balfe & Jackson, 2007). Participants’ use of insulin injections, for example, allowed their “dysappearing bodies” (the dysfunctional appearance of the body; Williams, 1996) to return to a less problematic state of embodiment in which the body “is characterised by absence” (Leder, 1990, p.1). The unity between body and self may become disrupted in illness (Charmaz, 1995) as it may be difficult for individuals to lead the life they wish as they focus on their body instead of acting from it.

Individuals in Balfe and Jackson’s (2007) study were able to engage in activities without having to focus on their diabetes due to the control the diabetes technology granted them. Thus, accepting the treatment regime may allow individuals with diabetes to feel more liberated from their condition than when they reject the treatment and the technologies. As such, patients should be informed that although the treatment regime and the diabetes technology may disrupt their routines at the beginning, adherence to the treatment may allow better control of their diabetes and lead to them being freer from it.

Thus, a variety of identity issues may affect the extent to which individuals adhere to their diabetes treatment regimens. The biomedical model has no framework with which to tackle or even recognize such issues as the patient is viewed as an object and the focus is centred on the underlying pathology of illness. The biopsychosocial model, in contrast, views the patient as a body-subject and recognizes the importance of psychological issues in the illness experience.

This research suggests that interventions dealing with identity issues may improve levels of treatment adherence. Future research in this area could address the potential of such interventions to improve treatment
adherence. For example, the research on diabetes has highlighted the way in which adherence to treatment may allow diabetes to recede into the background of the individual’s life as the individual gains more control over it. As such, a pilot intervention in which the benefits of treatment adherence are discussed with in patients may prove fruitful.

CONCLUSIONS
Both stigma and identity issues, psychosocial factors beyond the explanatory focus of the biomedical model, affect treatment adherence in diabetes. Taking these factors into account may increase treatment adherence. In order for this to occur, the explanatory focus of the current medical model must be expanded from one which focuses solely on the biological underpinnings of illness, to one, such as the emerging biopsychosocial model, which extends the foundations of the biomedical model to include psychological and sociological factors which impact on illness.
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