Chronic illness, labelling and stigma and pre diabetes.

Introduction

This paper summarises the sociological literature relating to the experience of chronic illness from the point of view of the patient / sufferer. It pays especial attention to the ways that the labels or diagnoses attached to particular diseases impact on the person's sense of self and identity. The stigmatizing and non stigmatizing nature of these labels is considered along with the ways that people cope with the illnesses that they have. The implications for the idea of pre diabetes are explored.

Symbolic interactionism and the study of illness

The background to the approach described in this paper is to be found in a form of sociological analyses called symbolic interaction which in the United States from the 1940s through to the 1970s was a highly influential (Rose, 1961). This was especially so among sociologists interested in the micro worlds of social life. Among many of the detailed aspects of social life which these writers explored was the experience of illness, especially long term debilitating chronic disease. Figures such as Anselm Strauss were hugely influential (Strauss et al 1984; Charmaz,, 1983, 1887, 1994, 1999) and brought a genuinely new perspective to light on aspects of illness which until that time had been scarcely described, and certainly had not been scientifically examined in the literature. They described the experience of illness, what it was like to be ill and the impact on the self and identities of people who were ill. They noted that that long term illness had an effect on the way people thought about themselves and thought about their place in the world in relation to other people. The idea that long term illness had considerable, especially economic impact was not of course new (Platt, 1979). The fact that illness especially long term illness affected employment and earning prospects, that it had effects on family life, friends, mobility and a range of other aspects of daily living was well understood. What however the interactionists brought into play was a consideration of the impact of the symptoms on the way people thought about them, managed them and related to others in spite of *and* because of the symptoms. What this sociological perspective showed was that the effects of symptoms went a great deal further than biochemical changes in the body to affect almost all aspects of daily living.

One of the most intriguing observations, which became clear once a range of illnesses had been examined in this way, was the fact that from a social and psychological point of view, illnesses as diverse as diabetes, emphysema, rheumatoid arthritis, and epilepsy had remarkably similar social and psychological sequelae, despite the fact that the symptoms, the aetiology and the prognoses were quite different. Disease has a profound impact on self – the person's sense of who and what they are - in ways that were uncannily similar regardless of the disease. In Britain the approach pioneered in the United Sates was taken up during the 1970s and a number of British scholars made major contributions to the genre including Bury, Locker, Williams, Kelleher, Lawton, Scambler and Pinder (Anderson & Bury, 1988; Bury, 1982, 1986, 1988, 1991; Locker, 1983; Williams, 1984; Kelleher, 1988; Lawton, 2003; Scambler & Hopkins, 1986; Pinder, 1990). This paper draws on the work of both the American and British writers.

Meaning, uncertainty and managing others.

In general the preferred method of data collection of these researchers was to use patient accounts of their illnesses as the principal basis for understanding their experiences. The argument was that it was important to view the experience, the phenomenon, from the point of view of the patient, and what better way to that than in their own words?

The meaning of the illness to the person and the problems of uncertainty that had to be managed on a day to day basis were of especial interest to these writers and featured in the sufferers' accounts of their experiences. A common theme was the search for meaning that the patients were engaged in. They would try to find the answer of why the illness had been visited upon them. These illnesses turned the patients' lives upside down, and this would cause them to try to find some explanation or meaning in this, often expressed as "Why me?"

Uncertainty and unpredictability were other very common elements in the experience. So for example in respect of rheumatoid arthritis the unpredictability of the pain, in epilepsy the unpredictability of the seizures, in ulcerative colitis the unpredictability of bowel movements all had common elements. It was managing the uncertainty rather than the pain or the bowel movement *per se* that was of significance, these researchers discovered.

They also discovered that managing the uncertainties and inconsistencies generated by the medical profession was a crucial task for the sufferer. A procession of physicians, nurses, specialist and others came into and out of the lives of the people with the chronic disease. These professional carers frequently had varying understanding of the problems and offered competing remedies and explanations. Sufferers acquired an expertise in the management of their own illness which their medical carers seemed sometimes only to have the dimmest understanding of. Yet, albeit for well intentioned reasons physicians would seek to impose particular medical solutions on the patient.

The patients of course had to manage other people's response to them and to their condition. So their disrupted movements, their unpredictable behaviour, their disappearances to take medication or to self inject were all things which interrupt the ordinary routines of social life and which undermine ordinary social behaviour. Learning to deal with others' lack of understanding and sometimes stigmatising responses, were intrinsic to the experience of illness.

Coping and resilience

What also characterised these accounts of living with chronic illness was the extraordinary resilience of the human spirit. It becomes very clear reading the reports that it is perfectly possible for people with chronic illness to enjoy a good, even a very high quality of life, in spite of the presence of the illness. The conventional wisdom was that bad precursors – disabling or disruptive symptoms – would have bad outcomes – a poor quality of life. But no; the quality of life of many people with these illnesses was in their own terms satisfactory or better than that.

The researchers went beyond accounting for this in terms of some psychological variable or personality characteristic called resilience and sought instead to understand the interactive

dynamics involved in these positive responses to a very negative set of physical changes in the body. They turned their attention therefore to understanding survival, coping and adaptation (Kelly, 1991, 1992a, 1992b)

A number of typical coping behaviours have been identified by this body of work. The first is *denial*. Denial, as the word implies involves some rejection of the illness. In essence the person refuses to acknowledge that they are any different to what they were when they were well. Their inner sense of self is one in which they declare that there is nothing wrong with them and they are as they always have been. On the other hand, their relatives, friends, and significant others see before them someone who is manifestly unwell, or at least different to what they were before. They see an ill person who is struggling with their condition. The fact that in this case the ill person's sense of self is discordant with the way others see them – their social identity - makes denial an inherently unstable strategy.

Because of this instability originally many commentators saw denial as a bad adaptive response, being seen as a flight from reality. However gradually observers began to realise that denial could also have positive psychological and other benefits (Lazarus, 1985). In the case of a chronic disease where there may be a gradual period of onset, where the symptoms were not at first as severe as they eventually become, or with an onset that is more sudden, an initial tactic of denial gives the person a period of time to get used to the idea, even while denying it, or of a metaphorical breathing space. In that space, they can begin to sort things out in their minds, before formally acknowledging their sickness both to themselves and to others.

The reason denial attracted such a lot of interest as an aspect of illness behaviour, was the fact that denial appears to be irrational. Why with the onset of symptoms did the person not immediately seek help and comply with their medical regimen as the classical paradigm of the sick role would predict (Parsons, 1951)? The answer was that denial seemed to function as a mechanism for making space and time to accept the diagnosis. And even acceptance was not some instant road to Damascus type of experience. What the researchers into chronic illness discovered was that acceptance was a gradual process characterised by recurrent periods of denial and rejection of the medical diagnosis. This is all the more complex because in many cases of chronic disease, either because people delay in seeking help, or because the disease is tricky to diagnose, quick diagnosis is unusual, with diagnoses taking time over a series of consultations.

The second coping strategy has been called *normalisation*. In this the behaviour the person with the illness does not deny the symptoms, but comes to see the symptoms as normal for them. This is common across many spheres of life and especially illness. So for example someone who is getting old might come to think of their breathlessness or their pains in their arm as just the normal aches and pains associated with getting old rather than as the symptoms of angina. The problem drinker might come to think of their early morning feelings of nausea as just part of getting up in the morning. And classically the morning smoker's cough is taken by the smoker to be normal for them. In the case of chronic disease the behaviour is similar. The fact that there are days when things are very painful for the person with rheumatoid arthritis is normal; for the person with type 1 diabetes the diet and use of insulin is just part of normal routine. With normalisation however, the the behaviour is not seen as normal by others. The degrees of incapacity are seen by others as real difficulties

and problems having a significant effect on the sufferer's life. While the sufferer constructs a sense of self in which they say "Its normal for me to be like this", others construct their identity as ill, "It's not normal to be like that , there is something wrong with you, you are ill". So in essence this too is potentially unstable. That is that while the self is saying "I am ok and this is normal for me", others at least have doubts and construct an identity in which the person is seen as sick.

The third strategy is very stable but dysfunctional. This is referred to as *resignation* or total absorption. As this implies, the person with the illness retreats fully into the role and plays out that role in full. Their illness floods their life. Their whole sense of self is taken over by the disease. It is as if they are saying that "The only significant thing about me is my illness and that is the basis on which I want to interact with you." They want others to see them as sick. It is stable if others do so reciprocate. Once reciprocation occurs, their identity as a sick person is constructed. If the role becomes stabilised in this way, the person who is ill essentially becomes completely submerged or absorbed into being an invalid. It is dysfunctional because, as was pointed out many years ago, there are some quite important psychological and other benefits attaching to the sick role (Parsons, 1951). The person is able to slough off responsibility for their condition and for trying to get better to others- their doctor usually. They are relieved of other normal adult social responsibilities like going to work or being responsible for others. And people will and do make a fuss of them. There is something childlike about the sick role and of being highly dependent on others and some people with chronic long term conditions may enjoy the care and attention that goes with being ill.

This process is what is sometimes referred to in the literature as the negative consequences of labelling. The classic exposition of this idea was that it is not the disease itself, but rather as the process of interaction between self and others which ensues which produces a label which in turn leads to the person being labelled internalising that negative identity or label and acting accordingly. In the case of the sick role if the particular illness does not carry a negative label, then it is all the easier for the label to be welcomed by the person being labelled. Presently type 2 diabetes does not carry much by way of a freight of negative meanings, most probably because in the public mind little distinction in aetiological terms is made between type 1 and type 2. This is important because where labels are negative or stigmatising as they are in some illnesses such as epilepsy or schizophrenia, interactive patterns will be very different. In this regard epilepsy has been extensively studied. So research has shown that people with epilepsy will often go to great lengths to conceal it from others, even though their actual experiences of being stigmatised in this way is not great (Scambler & Hopkins, 1986).

The argument that is sometimes made that labels or identities are inevitably negative or stigmatising needs to be treated with caution. Labelling is but the naming of a particular class of things or individuals according to some putative characteristic. It is the cultural responses to those labels which define them as positive or negative. What is clear is that some illness diagnoses seem to confer neutral or labels, such as influenza, the common cold, or diabetes whereas others seem to attract rather more negative ones. The responses to the idea of pre diabetes will be determined in the long run by the nature of the cultural beliefs surrounding the disease.

The last major coping strategy that has been identified in the literature is called *accommodation*. This is a relatively stable strategy too. What distinguishes it from the others is as follows. The self of the person with the illness acknowledges the fact of their symptoms and of the problems that those symptoms bring, and indeed as with normalisation the person may well come to see these aspects of their life as normal of for them. But the critical difference is that the person regards their problem as *but one component part* of their self and focuses for most of the time on other aspects of their life. So the fact that they are a parent or grandparent, a keen gardener, a football supporter, a member of the local church, an engineer or a student for example is regarded as much more significant to their sense of self, than their illness. Others respond and construct an identity which may acknowledge the fact of the illness or symptoms, but never the less focuses on the person as parent, gardener, and football fan or whatever it is. The person with the disease constructs a sense of self in which they will proclaim "I have a disease but is only a very minor part of my being. I want to interact with you on the basis of other personal characteristics and roles." Others reciprocate accordingly, "I will interact with you on the basis of roles and characteristics other that your illness". It is therefore stable and highly adaptive.

It is important to note that these four strategies – denial, normalisation, resignation and accommodation - are not fixed. They change over time and in specific situations and circumstances. Many people with chronic illnesses will at different phases and times in their illness act out different versions of these strategies. So when they are first ill perhaps denial will be the way they initially respond; as the illness develops or it worsens or goes into an acute phase, then the best response is resignation. Indeed when very ill, it is probably best to resign oneself to the illness rather than to try to fight it. As the person becomes increasingly used to the illness and the limitations it imposes on them then normalisation is a reasonable next step. And as things settle, particularly if the condition is well managed medically then accommodation is the mode of behaviour that may be adopted. And of course the social contexts in which people live, the amount of social support that is available to them, the resources that they have financially and otherwise, will all condition the possibilities of what they can do. The role that doctors play in all this is critical. What is important also to not e is that strategies are only partly determined by present symptoms.

It is also important to note that the habitual ways that they have learned to cope with things in the past will also have an impact. So if they have become used to dealing with problems successfully in the past and have developed a strong sense of self efficacy, it is likely that they will meet the problems that the illness throws up in much the same way. If on the other hand, they are used to seeing themselves a victim and as having little control over their destiny, a resigned response is much more probable.

Narratives of illness

One of the elements that has emerged in this arena of research is that the way people talk about their illness to others, including their doctors, provides important clues to the way that they are responding at any one time and the sense of self that they are presenting to others (Kelly & Dickinson, 1997). Some patients tend to talk in tragic terms about themselves and their illness. By this is meant a way of describing the story of their illness as a tragedy with themselves as the victim of a series of tragic events, in which they lay the blame for their current predicament on forces beyond their control for example incompetent doctors and the

quality of the NHS and so on. It is always the actions of other largely malevolent forces which explain the current state of affairs. Still others use stories of the classic epic form to describe themselves as heroes overcoming the slings and arrows of outrageous medical misfortune, but coming through it with fortitude and courage and indeed overcoming every obstacle that the illness can put in their way. These are the stories of resilience and of fighting back, of courage and fortitude, and indeed one does not have to be in the company of people with chronic illnesses for very long to find examples of these kinds of narratives and stories of the struggle and triumph over the odds. The other common narrative is something akin to comedy, not as a series of jokes, although self deprecating humour is not uncommon, so much as the presentation of self as the disinterested wry observer of events, casting a drollful look on the state of the world and the state of their health.

These classic narrative forms which originate in Ancient Greek myths and legends and come down to us in novels and films and television soap operas, are the stuff of everyday conversation between people. Not surprisingly therefore these narrative structures are used by people to describe their lives and the way they live with their disease. They are part of the way that they cope and they help to construct the sense of self which they use at the heart of their strategic coping behaviours.

Self and identity

Symbolic interactionism referred to at the beginning of this paper, used as one of is organising concepts, the idea of self (Ball, 1972). Although this is a word and an idea that is used in ordinary everyday speech, in symbolic interaction it had a very specific definition, viz, ego as known to ego. This means the idea we have in our mind's eye of what we are like. This will embrace the very obvious public roles we play, like father, husband, lover, scientist, builder, housewife and so on – bearing in mind that we occupy a whole number of these roles at any one time. It will also include the ideas we have about our personality and our own behaviour – of the type "I am a reasonable person", "I am fair", "I am angry". The self also embraces things which are very much in the here and now – I am a passenger sitting on a railway train travelling to work, I am a shopper buying Christmas presents, I am sitting in my garden. It also integrates more permanent things about me- I am six feet tall, I am a man, I am black. So self is an amalgam of some very substantial permanent things about us and some which are much more transient and determined by the situation or the immediate circumstances we find ourselves in. The other concept used by the interactionists was identity. This is not a synonym for self- which is often the way it is used in everyday speech; rather it is the views others have of us.   Our social identity is the way ego is known to others and is both permanent and plastic and divisible in the way that self is (Millward & Kelly, 2003; Kelly & Millward, 2004).

The really interesting thing, and this is especially so in the case of the illnesses with which we are concerned here, is that where self and identity are congruent, i.e. the way I see myself is pretty much the way others see me – then social interaction tends to flow along in a reasonably stable way. So if I have a sense of myself as a serious intellectual and so do others then stability will be the outcome. On the other hand if others view my intellectualism as a ridiculous vanity, then my claims to be taken seriously as that intellectual will be undermined. This is true of any social role constructed in interaction as self and identity are developed. In the case of the strategies described above, accommodation and resignation

were essentially stable strategies whereas denial and normalisation are unstable, where the views of self and identity are discordant. Still more important is the fact that as noted above, the self is divisible. It is made up of many aspects. We play many roles and in the course of a day, we may play many roles and occupy many identities. The accommodation strategy is important because it allows the illness to be but one aspect of the self or identity. Resignation is a strategy involving the whole self and identity.

The use of words here is highly significant because the person engaged in accommodation will talk about themselves thus :"I am a person with diabetes/ epilepsy/ colitis", whereas the resigned person will talk about themselves differently "I am a diabetic/ epileptic/ colitic". This idea is fundamental in dealing with the question of pre diabetes. Although the idea is contested it provides a useful platform for preventive activity before progression to the disease state proper. Clearly there is a danger that the label invites the resignation response or at least earlier resignation that might otherwise occur. This might still be further reinforced if there are strong cultural imperatives suggesting the inevitability of the appearance of diabetes and a fatalistic approach which suggest that there is little that can be done about it. The response of denial is of course potentially the most dangerous in the case of pre diabetes because it will lead to an ignoring of the problem and the potential for preventive activity to be missed. In this instance because of the slow and insidious potentially development of the condition, there is no sense in which denial can be viewed as adaptive; it is potentially highly damaging. The normalising response is potentially problematic too because it feeds off a fatalistic sense of inevitability which could militate against taking action when preventive activity could be highly efficacious.

The model of the accommodating response is therefore the *modus operandi* which needs to be worked towards with the individual or the group where the pre disease state is present. There are several elements to this. It involves the creation of identities and selves in which the physiological changes in the body are defined as but one part of the person and their bodily function, not the overarching and defining characteristic of it. At the level of self this pre disease state is something which it is potentially possible to act on, i.e. the person has a range of courses of action open to them which could be effective. These relate principally to diet and exercise.

In order to make this a reality, and borrowing further from the studies of chronic illness, there will be four types of skills which the person in the pre disease state needs to acquire to help bring about a more self efficacious response. First, technical skills relating to cooking, shopping, exercising, and weight loss are fundamental. These basic technical skills are the *sine qua non* of self efficacious activity. Second skills of an interpersonal kind, about how to relate to friends and family as dietary and exercise regimes change. Third, there are emotional skills to deal with the anxieties which will arise. To be told that one has an incipient and potentially serious illness, even tough it is not yet disease proper, is still a threat to valued aspects of self. So the person will need support to work through some of the problems and emotional and expressive feelings which they will experience. And finally, skills to help to make sense of the pre disease state. It is important to be able to make sense of what is going on. Type 2 diabetes is a modern epidemic. Its causes reside in the ways that we live in the modern world, the food we eat because it is available to us, the lack of easy opportunities to exercise and the more general obesogenic environment. It is a

modern ill, and it is important for people to see it in these terms rather than in terms of blame.

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