

“You Can’t Cure It so You Have to Endure It”: The Experience of Adaptation to Diabetic Renal Disease

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In this study, the experience of adaptation to diabetic renal disease was examined from a phenomenological perspective. Twenty patients attending a diabetic renal clinic were interviewed in depth. Through the use of a template analysis approach, a set of strong themes relating to changes in lifestyle was identified: changes in the nature of involvement with the medical system, coping strategies, and hopes, fears, and expectations. Almost all participants attempted to construct a “good adaptation” in the face of the uncertainties surrounding their condition by adopting a stoic and fatalistic stance. This is discussed in the context of the claim that contemporary society holds emotional self-expression rather than stoical endurance to be the appropriate response to suffering.

Diabetes is a relatively common disease that is estimated to affect at least 2% of the population. It has two main forms: Type 1 (insulin dependent) and Type 2 (non-insulin dependent). Type 1 is caused by the complete failure of the pancreas to produce the hormone insulin, which is responsible for the absorption of glucose into the body’s cells. It most frequently begins in childhood or adolescence, and without treatment in the form of regular injections of insulin, the sufferer will inevitably fall into a coma and die. Type 2 diabetes occurs when a person’s pancreas produces some insulin but in insufficient amounts. It can be treated by diet alone or by diet plus hypoglycemic tablets (which stimulate the pancreas to produce more insulin or make the body more receptive to insulin). A significant number of people with Type 2 diabetes receive insulin treatment when other measures prove inadequate—the term *insulin-treated Type 2 diabetes* is used to describe such cases. Both forms of diabetes are serious and result in reduced life expectancy from complications of the disease and from an increased disease-related risk of coronary heart disease and stroke. The development of diabetic complications is unpredictable, and there is considerable variability in the speed of their onset and the extent to which they interfere with a person’s daily routines. Diabetic complications can affect the eyes, the feet, the kidneys, or the nerve fibers in the peripheral or autonomic nervous system. As it is the main focus of this study, diabetic nephropathy (kidney disease) is discussed further below.

Diabetes and its treatment impose major constraints on patients' lifestyles, and this can lead to feelings of depression and a reduced quality of life (Lustman, Griffith, Gavard, & Clouse, 1992; Talbot, Nouwen, Gingras, Belanger, & Audet, 1999). People with diabetes may be more likely to suffer psychological disturbance (especially depression) than the general population (Lloyd, Dyer, & Barnett, 2000; Peyrot & Rubin, 1997), and those with diabetes-related complications may be particularly prone to significant dysfunction (Lloyd, Matthews, Wing, & Orchard, 1992; Peyrot & Rubin, 1997). Furthermore, the type of diabetes does not appear to be strongly related to either the level of depressive symptomatology (Friis & Nanjundappa, 1986) or the nature of patients' fears concerning the disease (Hendricks & Hendricks, 1998). The lifestyle changes required to manage diabetes can be extremely demanding for patients. Sullivan and Joseph (1998), for instance, reported that participants described the task of maintaining such changes as "a continuing battle." The psychological consequences of diabetes are thus potentially serious for many people with the condition, but it must be borne in mind that responses are highly variable and have been found to be related to factors such as age, gender, duration of the disease, and social support (e.g., Gåfvæls, Lithner, & Boerjeson, 1993).

Adaptation to Diabetes

A fairly substantial number of researchers have examined the psychological aspects of adaptation to diabetes. Given the emphasis on control in the management of the condition (i.e., adherence to dietary restrictions and treatment regimens and monitoring of blood glucose levels), it is not surprising that a major focus has been compliance (Hentinen & Kyngas, 1996) and, more broadly, factors influencing successful self-management (Anderson & Genthner, 1990; Clark et al., 1991). Although these are important issues for the medical management of diabetes, of greater theoretical interest to social scientists and health care professionals is the broader question of how people adapt to living with this incurable condition. It is quite clear that there is enormous variation in the psychological and social impact of diabetes on people's lives and that this variation cannot be explained solely in terms of the type or severity of the condition (White, Richter, & Fry, 1992). In attempting to understand such differences in adaptation, many researchers have seen a central role for the concept of coping. They have looked for relationships between factors influencing coping resources, such as quality of communication with medical staff, personality characteristics, and social support, and measures of psychological well-being (Littlefield, Rodin, Murray, & Craven, 1990; Sinzato et al., 1985). Sometimes, the relationships between coping and adaptation in diabetes have been compared to those found in other chronic conditions (Felton, Revenson, & Hinrichsen, 1984). Relatively few researchers have looked at adaptation to specific diabetic complications; where they have, the focus has tended to be on the area of visual loss (Cox, Kiernan, Schroeder, & Cowley, 1998; Wulsin, Jacobson, & Rand, 1991).

An important problem with much of this literature surrounds the use of the concept of coping as developed in stress research to refer to cognitive and behavioral responses to specific (mainly acute) stressors. In the transactional models of stress, which dominate this field, coping is seen as an attempt to correct the imbalance between demands and resources (Lazarus & Folkman, 1984) or to resolve a

discrepancy between the actual and the desired situation (Fisher, 1986). The implicit metaphor, as Radley (1994) pointed out, is that of coping mechanisms as “tools in a toolbox” (p. 150). Individuals need to choose the right tool for the job to cope successfully, and the role of health psychology is to provide expert guidance in making this choice. However, there is a fundamental problem with this approach when it is applied to adaptation to chronic illness. Implicit in the transactional view described above is the idea that successful or adaptive coping involves the return of the person to a healthy state of balance or concordance (i.e., an imbalance is countered or a discrepancy resolved). For instance, Zeidner & Saklofske (1996) stated that “ideally, adaptive coping should lead to a permanent problem resolution with no additional conflict or residual outcomes while maintaining a positive emotional state” (p. 508). This is an entirely inappropriate way of understanding the task facing the person with chronic illness, whose challenge is to find a way of living with a condition that has enduring and pervasive effects on his or her whole life. Reducing chronic illness to a set of stressors requiring particular coping mechanisms is a simplistic and impoverished account of the experience.

Another problem with many studies of psychological adjustment to diabetes (and to chronic illness in general) is the assumption—usually implicit—that problem-focused coping styles are in general associated with successful adaptation, this despite the fact that leading theorists, such as Lazarus (1999), emphasize that there is no one “right way” to cope. The bias toward more active, problem-focused types of coping in much of the literature—especially that aimed at professional and popular audiences—reflects the central place of notions of individual agency in the values of Western culture, as Antonovsky (1990) has pointed out. Researchers need to be wary of generalizing these values so as to define implicitly as maladaptive any coping response that is not active and control seeking. This applies particularly to diabetes because the variety and unpredictability of complications can result in enormous differences in the illness trajectories of sufferers.

Generalizations about “good adaptation” to chronic illness are also worrying in that they often take on a strongly moral tone. The traditional valuing of stoicism in West European and American societies (exemplified by the British stiff upper lip) has been reinforced by ideologies that accentuate personal responsibility for health (Williams, 1993). The good adapter is therefore characterized as the person who carries on with life cheerfully and uncomplaining while managing his or her condition efficiently and in obedience to medical instructions.

Diabetic Renal Disease: The Focus of This Study

We chose to focus on adaptation to one diabetic complication: renal disease. This condition affects about 20% of patients with Type 1 diabetes (McNally, Burden, Swift, Walls, & Hearnshaw, 1990). Renal disease also affects patients with non-insulin-dependent diabetes, but its prevalence is highly variable and dependent on geographical location. Renal disease can progress to end-stage kidney failure, which requires dialysis or transplantation to prevent death. Even when this does not occur, renal disease sufferers have a reduced life expectancy compared to other people with diabetes because of the associated increased likelihood of cardiovascular disease. They may be placed on a low-protein diet that is considerably more restrictive than the one they are used to and are likely to be asked to attend clinics

regularly to check on the progress of the disease. Good blood pressure control, particularly with angiotensin-converting enzyme (ACE) inhibitors, can delay progression to end-stage kidney failure (Lewis, Hunsicker, Bain, & Rohde, 1993). Nevertheless, the tone of medical texts on the condition is typically gloomy: "There is an awful sense of fatalism about renal failure in diabetes . . . once proteinuria [presence of protein in urine] is detected, the patient seems to take a steady downward path" (Fox & Pickering, 1995, p. 173).

Although there is a considerable literature on psychological adjustment to renal failure and dialysis (McGee & Bradley, 1994), almost no researchers have reported on it in the context of diabetes (a rare exception being Kopp, 1992). Therefore, in this study, we use a phenomenologically based approach to explore the patient's experience of adaptation to this condition. Within the broader aim of detailing the experience of adaptation to diabetic renal disease from the perspective of sufferers, we are particularly interested in the notion of the good adaptation and will address the question of whether, and in what ways, participants' accounts reflect the kind of societal moral judgments about living with chronic illness that previous researchers have described (Williams, 1993).

METHOD

A phenomenological approach was appropriate given our focus on individual patients' accounts of their experiences of adaptation to diabetic renal disease and the ways in which these may respond to prevailing social constructions of chronic illness. In particular, our position is very similar to Smith's (1996) "interpretative phenomenological analysis" (IPA), which draws on classic phenomenological psychology (Giorgi, 1970, 1995) and symbolic interactionism (Denzin, 1995) but also incorporates ideas from discursive psychology. Underlying IPA is the recognition that the accounts produced by research participants constitute attempts to construct a particular presentation of the self in the context of the interview rather than simple descriptions of "true" experience. However, unlike discourse analysis, researchers can use IPA to go beyond the text of the interview and develop interpretations of participants' experiences of the phenomena they are discussing.

Procedure

In this study, we used in-depth interviews to examine experiences of diabetic renal disease. Twenty-two participants were recruited from adult attendees at a diabetic renal clinic. They were selected to provide a cross section of patients in terms of progression of renal dysfunction (measured in terms of serum creatinine level¹), type of diabetes, range of complications, gender, and age. Ethical approval was given by the hospital's ethics committee, and potential participants were informed of the nature and purpose of the study, guaranteed anonymity, and given the right to withdraw at any stage without any implications for the future care they would receive at the clinic. Two patients withdrew from the study before the interviews commenced, leaving 20 interviewees. Table 1 shows participant details, including age, gender, renal disease severity, and diabetes type. Patients ranged in age from 36 to 69 years. All were White, and most were from a working-class or lower-middle-

TABLE 1: Number of Patients by Diabetes Type, Severity of Renal Disease, and Gender

	<i>Type 1 Diabetes</i>	<i>Type 2 Diabetes</i>
Moderate renal disease		
Women	4	1
Men	1	4
Serious renal disease		
Women	3	2
Men	3	2

class background. All suffered from at least one diabetic complication in addition to renal disease, including loss of vision, gangrene leading to amputation, peripheral vascular disease, heart problems, and impotence. Three of the patients with severe renal disease were on dialysis, 1 was on hemodialysis (hospital-based), and 2 were on continuous ambulatory peritoneal dialysis (CAPD, a treatment system involving the use of a portable dialysis bag, removing the need for attachment to a dialysis machine). There was no clear and consistent clinic policy at the time of the study regarding the use of low-protein diets. Some participants had been specifically recommended to adopt such a diet and others not, but all were following a standard diabetic diet and had been advised to reduce their intake of animal fat. Overall, the interviewees—whether severe or moderate in renal disease—would be considered by clinicians to be a group of actually or potentially seriously ill diabetic patients.

Interviews covered participants' histories of diabetes prior to diagnosis of diabetic renal disease, reactions to the diagnosis, the impact of renal disease on their lives (including their view of their diabetes), their involvement with the medical system, and their hopes and fears for the future. However, in keeping with the qualitative methodology, the interviewer imposed direction as little as possible, enabling participants to tell their own stories of diabetic renal disease. All interviews were audiotaped with participants' consent and transcribed in full.

Analysis

Analysis of the transcripts followed the template approach as described by Crabtree and Miller (1999) and, specifically, as developed by King (1998). This involves the construction of a coding template that comprises codes representing themes identified in the data through careful reading and rereading of the text. Codes are organized hierarchically so that the highest level codes represent broad themes in the data, with lower levels indexing more narrowly focused themes within these themes. It is important to note that codes are specified not only for themes found in most or all transcripts but also for those that are salient in only a small minority of transcripts. The list of codes is modified through successive readings of the texts until the researcher is sure she or he has achieved as full a description of the data as is feasible without reaching the state at which the description is so finely detailed that any attempt to draw together an interpretation becomes impossible.

Unlike some forms of phenomenological analysis (e.g., Hycner, 1985), it is normal in template analysis to define a priori a number of themes that reflect areas identified as particularly salient to the aims of the research project. Often, they

TABLE 2: Coding Template

<i>First-Level Code</i>	<i>Second-Level Code</i>
Immediate reactions or diagnosis	Strong negative emotion Lack of emotion Confusion Blame and injustice
Participant explanations of renal disease	Earlier lack of control Lack of information/misinformation from medical staff Fate Inheritance
Living with renal disease	Impact on lifestyle Involvement with the medical system Coping strategies
Hopes, fears, and expectations for the future	Outlook Treatment Development of the condition Uncertainty

NOTE: Integrative themes were stoicism and uncertainty.

reflect major topic areas in the interview guide. However, it is important to note that these a priori themes must always be seen as provisional and tentative and should be held open to modification or even deletion as the coding template is developed from its initial form to its final version. They are emphatically not rigid, predefined coding categories of the kind utilized in quantitative content analysis.

Producing the Template

Initial coding for main themes was carried out by CC. The template was developed further by NK and PN, each working on separate transcripts and then agreeing on a preliminary template. NK constructed the final template on the basis of a detailed rereading of the full set of transcripts. We defined four top-level codes, each subdivided into one or two further levels of coding. In addition, we identified two themes as common to all the main themes. These we termed *integrative themes*, as they cut across the vertical distinctions in the organization of the template. They served an important purpose in enabling a more holistic analysis to be produced than might otherwise have been possible. The first- and second-level and integrative themes coded in the template are shown in Table 2.

However, we did not attempt to produce systematic comparisons of different subgroups of patients (e.g., male versus female, Type 1 vs. Type 2). Given the lack of research into adaptation to diabetic renal disease, our aim was to produce a rich account of the experience from diverse viewpoints. By examining both the commonalities and the differences in experiences, we hoped to be able to highlight areas where more narrowly focused future research might usefully be carried out.

FINDINGS

The interviews were extremely successful in producing rich, complex, and often lengthy accounts of participants' experiences. Indeed, the volume of textual data has created problems in terms of its presentation; it would not be possible to deal with all four main themes in equal depth in the space of a single journal article unless we took a rather superficial approach. We have therefore chosen to concentrate here on the findings relating to the last two of the four top-level themes in the coding template, living with diabetic renal disease and hopes, fears, and expectations, as these most directly address the issue of adaptation and to the two integrative themes of stoicism and experiences of uncertainty. Please note that all names used for participants are pseudonyms.

Living With Diabetic Renal Disease

The central focus of the interviews was the participants' accounts of what it is like to live with diabetic renal disease, and a wide range of themes relating to this area were generated in the analysis. These have been grouped under three second-level themes: impact on lifestyle, involvement with the medical system, and coping strategies. Within each of these, we describe the major issues of concern raised by participants, examining in particular how these relate to the account of their adaptation to renal disease presented by them.

Impact on lifestyle. For most patients, the onset of diabetic renal disease requires adherence to a low-protein diet that is markedly more restrictive than the standard diabetic diet. One woman, a practicing health care professional, outlined the potential impact of the diet very clearly:

We were trying to work out how I could cut down on my protein, and we do go out a lot and have a good social life, and I got thinking, "I don't have any fat in my diet, I don't have anything sweet unless it is fresh fruit, when you cut out protein I don't think I will have anything left. I will have a bare plate in front of me!" (Simone)

For several participants, the dietary restriction of diabetic renal disease was a major theme of loss in their interviews. Their inability to enjoy foods that they had been able to eat at least in moderation on a standard diabetic diet seemed to symbolize the gravity of the transition in their condition associated with renal disease. The strongest example of this was from a 41-year-old man with Type 2 diabetes, who repeatedly returned to the subject of food, especially his passion for cheese, throughout his interview:

The wife tells me all the time [pause], "Cheese again, cut down on the cheese." But it's my only pleasure [pause] not my only pleasure, but it seems such a little thing, you know, it's not like drugs or smoking or drinking, I know I keep going on about that [pause] it seems so trivial, having a piece of cheese. (Barry)

The impact of diabetic renal disease on diet can be seen as a special instance of the wider impact of the condition on family and social life. The support (or, less

commonly, lack of support) given by family members was a common theme across these interviews. Many participants felt that their diabetic renal disease and other complications had led them to become more dependent on family members than they had been at an earlier stage of their diabetes. Much of their description was that of practical support, such as reminding them to take medication, ensuring they adhered to their diet, or carrying out domestic tasks that they now found difficult. However, participants were often at pains to emphasize their efforts to minimize their reliance on others:

Mother-in-law's very good, and me friends are great! You know. They all said, "We're on the end of a phone if you need us," you know, but I'm a very independent person, I like . . . you know, I won't myther [bother] anybody, unless it's really really necessary, you know. But they're there if I need them. (Vera)

Many participants felt keenly the restrictions on family and social life. For example, a 35-year-old woman (Type 1 diabetes) with a young family complained that because of her treatment regimen, she always needed to plan family activities in advance:

I find I can't just up and go on the spur of the moment, or even say, "Well, let's go to Blackpool"; I couldn't just up and go. I find that annoying. I would love to be able to do things just on the spur of the moment without having to plan anything. (Wendy)

Some participants stated that diabetic renal disease had had an important impact on their working lives. Several had given up work or changed to part-time jobs because of it. The sole participant on hemodialysis, Michael, was forced to give up the job he loved because of his treatment, and this had clearly contributed to his sense of worthlessness and his depression. For those who continued to work, the worsening of their diabetes associated with diabetic renal disease sometimes created new problems. Wendy complained about the lack of understanding shown by her work colleagues:

We might be counting money and it is gone past my lunch and we'll not be ready for another hour, sort of thing, and they don't understand the significance. I mean, I feel as though I have got to be forever explaining and I find it embarrassing, to be honest. (Wendy)

Involvement with the medical system. Participants frequently reported that developing diabetic renal disease had led to changes in the nature of their involvement with the medical system. These included changes in relationships with doctors and other health professionals and new or increased demands of self-management.

Although many participants recognized an increased reliance on doctors, the way in which this was manifest differed considerably between cases. At one extreme were those who had little interest in gaining a detailed medical understanding of their condition and were happy for the doctors to be in control, seeing their own role as complying with expert instructions:

I mean as long as I know . . . that we are going the right way I am quite happy to leave the management of the medication up to him [consultant diabetologist]. I mean I will manage, I don't think the diabetes is too much of a problem now that I can look

after myself, it is just the side issues now that I am letting other people look after for me. (Thomas)

Note the way that this participant distinguishes between “the diabetes,” which he is able to manage himself, and the complications (“side issues”), which he delegates to the experts. This desire to claim responsibility for at least some aspects of dealing with their illness is typical even of the patients who (as here) were the least concerned about understanding and making medical decisions about their condition. They differed from the others in that they presented themselves as essentially reactive in their self-management, responding to the instructions of doctors. Others were more proactive, wanting to understand the medical explanations for what was happening to them and to be actively involved in decision making. A good example is Quentin, a 49-year-old man, who gave up work to concentrate on controlling his diabetes after being diagnosed with renal disease. In relation to receiving encouraging renal test results, he said,

To me, I have achieved that test, that result, I have with their help. They have decided on the treatment and how much of this I have got to take, and I have got to do this and I have got to eat that, and I stuck to that. So it is not them that is motivating me to stick to that treatment, it is the fact that I understand that if I don't I would deteriorate. (Quentin)

Regarding self-management, participants reported more difficulties in keeping to their diet than in taking medication appropriately. However, it must be noted that not everyone experienced a conflict between accepting dietary restrictions for the sake of their health and maintaining a worthwhile quality of life. Where problems with medication were discussed, they were mostly in relation to remembering to take tablets regularly. Some participants with multiple complications were taking a large number of different medications every day; one described herself as “a walking pill.” None of the insulin-dependent or insulin-treated cases reported significant problems with taking their insulin regularly, although a few had had difficulties with reactions to different types of insulin.

In examining how participants experienced treatment regimens, we must consider separately those who were on dialysis. Of the three who had started on CAPD, only one—Michael—chose to change to hemodialysis. He did not make explicit the difficulties he had had with CAPD but strongly implied that his anxiety about the treatment, especially the self-management involved, played a major part in his decision to change to a hospital-based treatment. Although he found hemodialysis more acceptable, he still talked about it in mostly negative terms, with no attempt to downplay its disruptive impact on his life. His account contrasted very strongly with those of the two women on CAPD. One, who had been on dialysis for only a few months, admitted that it was not easy to get used to it and that she had yet to feel the benefits of it; she expressed confidence, however, that there would be benefits in time. Vera, who had been on CAPD for about 2 years, presented her preference for it in terms of the greater freedom it gave her. Despite finding the operation to attach it very unpleasant and still experiencing some discomfort with it, she described the self-management of dialysis as something she rapidly integrated into her daily routine. She also pointed to the positive side of CAPD, that she was allowed a less restrictive diet.

Coping strategies. Coping strategies include the actions taken and the outlooks adopted by participants in response to the task of living with diabetic renal disease. For most, stoicism was a major element of coping: “carrying on” as best they could, causing as little “fuss” for others as possible, and trying to look on the bright side while accepting whatever was to come with quiet resignation. Rita, who had multiple diabetic complications, including visual loss, peripheral vascular disease, and neuropathy, and had suffered amputation of both legs, repeatedly stressed how “lucky” she felt.

However, there was considerable tension in many of the accounts between this stoical stance and the admission of feelings of depression or despair. The struggle between contrasting self-presentations—resilient copier versus desperate victim—was extremely vivid within certain interviews. Rita, a 60-year-old woman with Type 2 diabetes and severe renal disease, is a good example of this conflict, alternating between typical stoical statements (“I shall just keep plodding on”) and confessions of severe anxiety:

I try not to worry about it. I do worry sometimes. I have some sleepless nights some nights, and when I do start to think about things and I think, “Oh my God” [pause] you know, if I’m feeling a little bit, say you’ve had a bad cold and you’re feeling a bit rotten [pause] you start thinking about things, you know, and you have a sleepless night about it wondering and worrying about it. But on the whole I [pause] I carry on and don’t bother. (Rita)

More than half the participants made some attempt to downplay the seriousness of renal disease, especially by comparing it positively to other illnesses or other diabetic complications, or by comparing themselves to the other diabetic renal patients they knew. Often, though not always, such downplaying appeared to be directly linked to a stoical outlook; the observation that others are worse off than oneself served to legitimize forbearance and preclude self-pity or sympathy seeking:

There’s people inject four times a day at least, you know. And then when you go to that kidney clinic now, you see them in wheelchairs and you think, “Thank God I’m not as bad as that.” You can’t keep on being miserable. I can’t anyway. (Yvonne)

Another common aspect of coping strategies was the search for control. Many participants recognized that the onset of diabetic renal disease meant that they needed to take their diabetes more seriously in terms of adherence to dietary advice and treatment regimens. However, in a few cases, the desire to minimize further kidney deterioration through strict control seemed to have taken a dominant role in the person’s life. This was most evident in the account of Quentin. Throughout his interview, he referred to the importance of control in how he coped with his diabetic renal disease. Even when talking about the need to rely on family members, he did so in terms of his active role in clarifying for them what they should do in an emergency:

I have got a daughter, she is married now, she is 22, and a son at 24. Yes, they understand. I have explained to them the treatment and they understand what it does and the complications and what to do if something does go wrong. (Quentin)

We have seen that diabetic renal disease was often associated with feelings of loss and limitation in areas such as diet, work, mobility, and social contacts. These were usually talked about as “effects” of diabetes and diabetic renal disease, but a few participants attempted to present such changes within the context of a coping strategy of “taking it easy.” This enabled them to retain at least some sense of agency in their response to the condition:

I take things easy, I don't exert myself now, because if I do I get out of breath quick, so I don't do any heavy work now. . . . If we go shopping and I carry any bags or anything, it puts me out of breath quicker, so I take things easy. (Bernard)

Hopes, Fears, and Expectations for the Future

Three second-order themes were defined within this main theme: the general nature of participants' outlook toward the future, their concerns and anticipations regarding specific types of treatment, and their expectations regarding the development of their condition.

Outlook. This theme was closely linked to the current coping strategies described by participants, as discussed in an earlier section. Again, stoical endurance was predominant. Relatively few talked about the future in terms of either hope or despair; most portrayed themselves as carrying on as best they could, living from day to day, and accepting fatalistically whatever changes they faced:

That is my attitude: Get on and enjoy life and do what you can, and if there is something you can't do then you have just got to put up with it. So I think I have just developed that attitude, worry about it if you come to it. (Simone)

Some participants dealt with the possibility of future deterioration by emphasizing the quality of life they had achieved up to the present despite their diabetes and its complications. We have already noted the case of the woman who had suffered loss of vision and double amputation but insisted on calling herself “lucky” and resented any sympathy for her condition. Another participant said,

What is going to happen is going to happen. I have had a good innings. I have got two kids I thought I would never have. I have really got around. (Wendy)

Many of our participants told us that they made conscious efforts to avoid thinking about the future progression of their renal disease and/or diabetes in general. They were very aware of the possibility of deterioration and further complications but felt that to dwell on these was at best unhelpful and at worst frightening. In some cases, participants said that initially they had worried about the future but now had adopted a fatalistic outlook that enabled them to carry on with their lives without being constant preys to anxieties about their condition:

When you know [renal disease] can't be reversed, you feel, you know, “am I going” [i.e., dying] kind of thing. . . . But after a while you get “what's the point?” Yeah. You can't cure it so you have to endure it, kind of thing. (Yvonne)

In cases like this, avoidance of thinking about the future was not used as a way for participants to hide from their problems, as "avoidant coping" is often depicted in the popular stress/coping literature; rather, it was a way of directly and consciously addressing the task of adaptation. To become preoccupied with the uncertainties of the future would undermine the strategy of stoicism, which was, as we have already seen, the orientation to their condition adopted by almost all the participants. Worries about the future were not denied, as the following sections make clear, but neither were they permitted to overwhelm the person. Annie remarked, "If you do give in you might as well become a cabbage and sit in a chair and that is not me. I won't give in."

Avoiding worries about the future was more of a struggle for some participants than for others, and in certain cases there was a sense that their outlook of acceptance and endurance could easily be undermined by the unexpected. For instance, a misprint in a letter informing clinic patients about this study led one woman to become seriously frightened that she now had problems with her liver. (The interviewer, of course, reassured her that this was not the case and explained the error.) In fact, almost all those interviewed admitted to some worries about the future, but only one, Michael, described an outlook entirely of hopelessness and despair.

It is striking that although Michael was the only patient who was entirely negative about the future, very few expressed any outright optimism either. In fact, only two cases presented any kind of optimistic outlook. One was Thomas, a 44-year-old man (Type 2 diabetes, mild renal disease), who claimed not to have had any kidney deterioration and was relatively untroubled by the possibility of it occurring in future. (This was the only participant whose stance could be described as one of denial.) His optimism seemed to be associated with a very positive view of medical progress; he stressed the advances in treatment of diabetes he had seen in his lifetime, and expected these to continue: "I can see things getting easier for diabetics, well, for everybody, steps are being taken, medical research, and the work being done here, the work you are doing is part of that research."

The other case was Vera, the 45-year-old woman with severe renal disease (Type 1 diabetes) who was on CAPD. She had been offered the possibility of a kidney transplant and perhaps even a kidney/pancreas double transplant. She was excited about this but at the same time was wary of putting too much faith in it:

If me mother was alive, she wouldn't believe it. She wouldn't. She would not believe. If I turned round to her, like, if I was to turn round to her and say "I'm goin' to have a pancreas operation 'n' uh I won't be a diabetic any more", she'd say "Give over!" [laughs] (Vera)

Treatment. It is notable that the optimism of both participants just quoted was associated with treatment. Possible changes in treatment figured in many accounts, but mostly as a cause for concern or fear rather than hope. By far the most discussed treatment was dialysis; of the 17 participants not currently receiving any form of dialysis, 14 made some reference to it as a possibility in the future. Feelings about the possibility of dialysis were (not surprisingly) mostly negative, though some were much more worried by the prospect than others. Rita described herself as being "frightened to death" by dialysis; when the interviewer probed as to why, she simply said, "Just the thought of it." On the whole, participants did not seem to have

a very clear idea as to what dialysis actually is. When Yvonne was asked why she was fearful of it she replied,

I don't know. I don't think about it. No. I don't know why. I think it's, you know, the needles and I know nothing about it. And I think like a lot of things you know nothing about, you have a fear of them. (Yvonne)

Yvonne is typical of many in this sample in that her main strategy for dealing with the fear of dialysis was to avoid thinking about it. There is a potential vicious circle here, in that the desire to reduce anxiety by avoiding thinking about dialysis may lead people to avoid information about it, but (as Yvonne recognizes) ignorance about the procedure may itself generate greater fear of it.

In contrast to dialysis, the possibility of kidney transplant was considered by only a minority of participants. Yvonne, whom we quoted above, was by far the most optimistic; others generally took the view that they should not "get their hopes up." Several were concerned about the availability of kidneys for transplant and their eligibility to receive one. In the case of Michael, the fact that he had been on a waiting list for transplant for a long time appeared to have added to his sense of desperation.

Development of the condition. Despite very widely varying degrees of understanding of renal disease, all the participants bar one were clear that damage to the kidneys could not be reversed. Even the sole exception, Clive (a 60-year-old man with moderate renal disease), was not at all convinced of the possibility of recovery of kidney function; he was simply uncertain whether some slight improvement might be possible.

A few participants were hopeful that their kidneys would remain stable indefinitely, but more recognized that further deterioration was likely. They generally dealt with this through the kind of stoical and fatalistic outlook described in previous sections. Specific fears included further restrictions to lifestyle and becoming a burden to others. For many, kidney deterioration was less of a concern than the development or exacerbation of other complications, including neuropathy and the risk of amputation, incontinence, and, above all, blindness.

For more than half the participants, consideration of possible deterioration in their condition led them to discuss their own mortality. Most did not want to dwell on the topic but mentioned the need to make the most of life and avoid worrying about death. Several were worried about the effect their death might have on their family, and Rita implied that a decent quality of life was more important than prolonging life at any cost: "I don't think anyone wants to die, do they? . . . I think I wouldn't like to live to be, I'd hate to be put in a home or anything like that."

DISCUSSION

We have sought to produce an understanding of the experience of adaptation to diabetic renal disease through an examination of the accounts of 20 individual sufferers. Using template analysis of the interview transcripts, we have shown that there was considerable variation in this experience among our participants, but there

were some strong common themes as well. Without downplaying the uniqueness of each person's adaptation, in this final section we focus on the two integrative themes that emerged as strongly characteristic of this set of data: the use of stoicism as a strategy for achieving a good adaptation and the challenges it presents and the experience of uncertainty in the process of adaptation.

Stoicism and the Good Adaptation

We have seen from writers such as Williams (1993) and Radley (1994) that adapting to chronic illness is not simply a matter of sufferers finding ways of coping with their condition that suits their individual needs. Because the chronically ill have to find ways of "living with illness in the world of health" (as Radley puts it), they need to adopt strategies that meet with the moral approval of those around them. Coping is not principally a matter of how one thinks about oneself (appraisal, in the language of transactional stress models) but rather a matter of how one presents oneself. Our participants used a range of ways of presenting themselves in relation to their illness, including control seeking, denial, optimism, and defeatism. However, without question, the dominant strategy was stoicism. The case of Michael stands out so clearly because of his failure to make any attempt at stoicism in the account he gives the interviewer.

Why should stoicism be such an attractive strategy for the diabetic renal disease sufferers we interviewed? Following our argument above, it seems very likely that the value and approval it is accorded by others plays a key part in this. This explanation would once have required no further justification—it was indisputable that British (and indeed North European and North American) society saw stoicism as the appropriate response to suffering. However, over the past decade or so, many commentators have observed that stoicism has fallen from favor, replaced by emotional self-exposure, the "victim culture," and the turn to professional sources of support such as counseling. Academic writers have drawn on Foucault's critique of the "psy-complex" to highlight the increasingly confessional nature of our society (e.g., Burr & Butt, 1999), and popular authors and journalists have cited public reactions to the death of Princess Diana as evidence of a sea-change in public attitudes to emotional openness (Marr, 1998).

We are therefore left with the question of why our participants (and perhaps chronic illness sufferers more generally) have continued to adhere to a traditional stance of stoicism. Demographic factors may well be important: The mean age of our participants was 49 years, and most were from northern England and from working-class or lower-middle-class backgrounds. All of these characteristics may tend to predispose an individual toward a more conservative outlook on emotional self-disclosure than we might see in a younger, metropolitan, middle-class sample. However, we do not feel that this alone is sufficient explanation; after all, there was no indication that the younger or more middle-class participants in our group tended to be any less stoical than the rest. The fact that the interviewer was a medical student must have influenced the way participants presented themselves; arguably, they may have been less willing to appear unable to "cope" to her than to a layperson. We feel, though, that it is unlikely that the stance adopted in the interviews was purely a response to the medical knowledge status of the interviewer. The interviewer emphasized her identity as a student and her relative lack of

professional knowledge, and there was little evidence that participants were unwilling to discuss issues that might reflect badly on doctors (for example, inadequacies in past medical advice and treatment).

We would contend that tolerance—even encouragement—of emotional self-disclosure in response to suffering is limited according to the nature of the suffering involved. Such a presentation may be applauded when it is seen as a means of “getting over” a traumatic event (or sequence of events), of helping to put it in the past. It is therefore deemed appropriate in circumstances such as bereavement, recollection of childhood abuse, or relationship breakdown. The very nature of chronic illness is that there is no getting over it; it is always in the present. In these circumstances, continuing revelation of emotional turmoil would only serve to alienate the chronically ill from the healthy world.

Uncertainty

Uncertainty is clearly evident in participants’ accounts of their hopes, fears, and expectations for the future. It can be seen in relation to the continuing effectiveness of and the possibility of changes to treatment, the threat of side-effects, the availability of transplants or dialysis machines, the prognosis for their renal disease, and the likelihood of further complications of diabetes. Regarding living with diabetes, uncertainty was apparent particularly in relation to treatment, with many participants unsure of the purpose of the medication they were taking. To some extent this uncertainty reflects the nature of both diabetes and renal disease, in which the medical profession cannot necessarily give firm predictions in particular cases. For some of our participants, it also reflected their limited comprehension of their condition and ambivalent feelings about gaining a fuller understanding.

Uncertainty has, of course, been widely observed and discussed in the research literature on chronic illness (e.g., Gordon & Benishek, 1996; Mason, 1985, in relation to diabetes; Pierret, 1992, in relation to AIDS; Smith, Flowers, & Osborn, 1997, in relation to chronic pain). However, we should not assume that uncertainty is manifest in the same form and with the same impacts in all chronic illnesses. In diabetic renal disease, the peculiar feature of uncertainty is that it is interwoven with a near-opposite experience, namely, the “awful sense of fatalism” described earlier in the quote from Fox and Pickering (1995). Trapped between the many sources of uncertainty we have identified and the prognosis of seemingly inevitable decline, we would argue that stoicism (with a strong fatalistic tinge) represented the only viable alternative to depression and despair for most of our participants.

Suggestions for Future Research

In this study, we have attempted to unravel some of the important threads from which the experience of diabetic renal disease is woven. In so doing, a variety of avenues for future research suggest themselves. First, it would be useful to examine how well the kinds of accounts of adaptation described here correspond to the assumptions of the dominant theories of health transitions in the literature. For example, could adaptation to diabetic renal disease be viewed as a psychosocial transition of the kind Parkes (1988) describes? Our evidence suggests that there might be problems with such an approach because people vary considerably in the

extent to which they see the onset of a complication of an existing chronic condition (i.e., diabetes) as a transition point in its own right.

Future research could also involve the kind of systematic comparison between patient groups that we chose to avoid in our analysis. Taking the Type 1/Type 2 distinction as an example, there could be some consistent differences in patterns of adaptation relating to differing popular understandings of diabetes. It is a common lay belief (though medically inaccurate) that Type 1 diabetes is more serious because of the sufferer's dependence on regular injected insulin. One might therefore hypothesize that people with Type 2 diabetes would be more likely to be unprepared for serious complications of diabetes than Type 1 sufferers and therefore might experience the onset of the complication as a greater disruption to their life world. Studies carrying out such group comparisons (whether qualitative or quantitative) may provide a deeper understanding of how people adapt to conditions such as diabetic renal disease, but researchers must be wary of allowing their own prior assumptions to color their designs, analyses, and interpretations.

A third potential area for future research centers on the issues concerning stoicism as a coping strategy, which formed such a strong theme in our analysis. We have suggested that although there is now a much greater valuing of emotional self-expression—and the related devaluing of stoicism—this does not apply to all types of suffering and misfortune. Specifically, stoical endurance may remain the dominant coping strategy in situations such as chronic illness, in which getting over the condition is not seen as a possibility. We are, of course, not suggesting that this is the sole explanation for the favoring of stoicism by our participants. Nor do we propose this as a general account for all persons' experiences of all chronic illnesses—there is, for example, a growing literature of autobiographical accounts of cancer (e.g., Diamond, 1999; Picardie, 1998). Nevertheless, we do feel that the tension between values of emotional openness and stoical endurance is a potentially fruitful area for social scientists studying the experience of chronic illness.

NOTE

1. Patients with serum creatinine levels $>210 \mu\text{mol/l}$ were classed as *severe*; those with serum creatinine levels $<210 \mu\text{mol/l}$ were classed as *moderate*. This threshold creatinine level was the median value in the nephropathic population.

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