In this section we present some examples of what IPA studies look like once they have been written up. The aim is to give the reader an idea of what the procedures laid out in Section A are leading towards. Each of these studies is from our own work and each represents a study in its own right. We also think these are good examples of IPA. The examples are taken from Jonathan’s work on dialysis treatment for kidney failure and on the transition to motherhood (Chapters 7 and 10), Paul’s work on gay men’s attitudes towards sex and sexuality (Chapter 8) and Michael’s work on psychosis (Chapter 9). Thus they also illustrate the breadth of research topics IPA can be used for. Each chapter is also particular in that there are certain features of the IPA approach it demonstrates. These are summarized in a box at the beginning and discussed at appropriate points in each chapter. All names mentioned in the studies have been changed to protect confidentiality. And each chapter also contains a brief guide to some other IPA work in the area. The box below indicates the transcript notation we have used in these chapters.

Transcript notation used in quoted extracts in Chapters 7–10

... significant pause
[] material omitted
[her husband] explanatory material added by researchers
Introduction

There is now a considerable body of work using IPA to explore issues in the personal experience of health and illness. This chapter will present a detailed illustration from a study by Jonathan examining one patient’s experience of the psychological impact of haemodialysis treatment for kidney failure. What emerges from the analysis is the powerful ways in which the disease and treatment can be seen as undermining the patient’s sense of identity. This example will illustrate what an IPA study looks like in practice but will also exemplify the approach’s idiographic commitment as the data is drawn from a single participant. The particular features of IPA highlighted by this study are summarized in Box 7.1. At the end of the chapter is a short description of some other studies using IPA to explore aspects of health and illness.

Box 7.1  Particular features of the study in this chapter

- Presents a single case study of one woman’s experience. This is consistent with IPA’s idiographic commitment and enables detailed understanding of her particular experience but also entrée to Warnock’s notion of shared humanity.
- Illustrates Heidegger’s notion of ‘appearing’. One element of the woman’s account seems, at the surface, not to be about dialysis at all but its latent meaning appears during the analysis.
- Offers a good illustration of the hermeneutic circle, as part of the material is seen as illuminating the whole and vice versa.
- Works towards a single overarching theme – ‘the undermining of identity’.
Dialysis and the undermining of identity: A case-study of the psychological impact of haemodialysis treatment for kidney failure

Background

Haemodialysis is a treatment regime for end-stage renal disease (ESRD). During dialysis, the patient is connected to a machine which extracts, cleanses and replaces the blood, taking over the function of the damaged kidneys. Treatment sessions are long and frequent, commonly lasting three or four hours, three times a week, and can take place either in hospital or, if the patient has their own machine, at home.

Dialysis is a treatment which is protecting the individual from a life-threatening disease. However, research suggests the treatment can have deleterious psychological effects paralleling those associated with the condition it is intended to treat, and high levels of depression are reported (Watnick, Kirwin, Mahnensmith, & Concato, 2003). In health psychology, issues of perception of control are often important theoretical constructs. Dialysis treatment is typically correlated with high degrees of perceived external locus of control, that is to say the patient has very little sense of personal control (Martin & Thompson, 2000), and where internal locus of control is found it is coincident with positive adjustment.

Most existing studies on ESRD are quantitative, isolating discrete independent and dependant variables and modelling relationships between them. While these studies help provide an overview of the topic, their predominance has been at the expense of work which would attempt a more detailed examination of the phenomenology of the individual’s response to ESRD – an equally valid psychological enterprise. A small number of studies do help provide the richer picture of coping with serious kidney disease, to supplement the broader quantitative canvas.

Reichsman and Levy (1972) followed ESRD patients for 4 years from beginning dialysis and found that, typically, patients pass through three stages in their response to treatment. A honeymoon period lasts up to 6 months as the patient expresses pleasure at being relieved from the serious acute condition which led to the requirement for dialysis. A period of disenchantment follows and may last for up to a year, as the unrelenting burden of treatment begins to take its toll. During this period the patient may suffer severe depression or attempt to deny aspects of the illness. Finally a period of long term adjustment ensues and the patient begins to accept their illness and the effect it is having on their life.

A grounded theory study by Gregory, Way, Hutchinson, Barrett, & Parfrey (1998) examined the responses of Canadian dialysis patients to their treatment regime. The paper discusses the range of emotional and physical reactions of participants, their attitudes to staff and family and their beliefs about illness and treatment. The paper makes a useful contribution to the literature, grounded as it is in accounts obtained from patients from which illustrative extracts are provided.
From their content analysis of Swedish hospital haemodialysis patients, Hagren, Pettersen, Severinson, Lützen and Clyne (2005) elicited three main themes. Participants spoke about the various restrictions dialysis placed on them, for example in terms of work and recreational activities. They described their reactions to the treatment process, for example in terms of emotional distance from the staff. They also pointed to ways of trying to manage the restrictions imposed by dialysis.

The study reported here intends to explore in detail the personal meaning of dialysis. It employs IPA in order to examine the impact of undergoing haemodialysis and how the patient attempts to make sense of it. We argued in Chapter 2 for the idiographic mode of inquiry and the important and neglected role of the single case in psychological inquiry. Thus, in order to capture in detail the experience of dialysis treatment, this chapter reports on one woman's account of it. However, as we argued earlier, the case does not exist in splendid isolation. It can then be used to dialogue with constructs in the existing literature and further, as Warnock (1987) suggests, the particular and general are not necessarily antagonistic. By learning in great detail about the individual case, we are thus better positioned to consider how, at the deepest level, we share much with a person whose personal circumstances may initially seem entirely separate from our own.

Method

Carole is the patient taking part in this study. She is 44 years old and has been dialysing in hospital for six months. Thus, according to Reichsman and Levy’s model, she is approaching the end of the honeymoon period. Carole has a partner and two children. All identifying information has been altered in order to protect confidentiality. Carole was approached by the renal-unit counselling nurse to take part in the study and the counsellor explained that the study was being conducted by a researcher who had no connection with the hospital she attended.

Carole was interviewed in hospital before beginning one of her dialysis sessions. The semi-structured interview followed the guidelines outlined in Chapter 4. Examples of questions on the schedule are: ‘What do you do when you are dialysing?’ ‘How does dialysis affect your everyday life?’ The interview was audio-recorded and transcribed verbatim and the transcript was analysed according to the procedures outlined in Chapter 5. In this case, a single superordinate theme or gestalt ‘undermining of identity’ emerged through the analytic procedure. This appeared to make sense of the participant’s experience and the analysis is therefore organized in terms of this concept. A small part of the data and analysis first appeared in Smith (1996).

Analysis

‘Becoming part of this machine’. While Carole recounts that she was positive towards the treatment when it began and was first experiencing relief from...
the symptoms associated with kidney failure, by six months her attitude has changed dramatically and she vividly captures the physical demands of dialysis:

I have become a bit more negative about it. [ ] I was really positive about dialysis [in the beginning] [ ] but now the feelings I have of, yeah loss of identity, being sort of tethered to one place and to this machine and becoming part of this machine. [ ] You’re just so sort of passive in the whole situation cos once the machine is in operation you have to keep still and you can’t move much otherwise the damn thing alarms all the time.

The dialysis is physically very restricting, allowing very little movement during the three hour session. The description suggests the confinement of a prisoner or even of a captured animal. The impact on self is clearly an important construct for Carole. The interviewer made no prior reference to identity. Carole herself brings it to the forefront of the discussion. Note also the direction of the process described. The machine is intended as an enhancement or extension of the self. However for Clare it works the other way as she is ‘becoming part of this machine’.

The regime is unrelenting:

At first it was a bit of a novelty and it was treatment that was doing me good. And now it’s like as I say just repetitive and time consuming and the worst bit is like going home afterwards and feeling an absolute wreck you know really tired out and fit for nothing and totally drained. And when I go to bed that’s my sort of lowest ebb of thinking oh God you know I feel like this again I’ve got to face it all over again in two days’ time.

Thus the regularity of the dialysis treatment means as soon as Carole is over one session she is already preparing herself for the next one.

However, as Carole herself makes clear it is the institutional contextualization of the temporal and spatial entrapment that has the greatest impact on her sense of self:

When you go on the machine you’re a part of it. You haven’t got an identity on that floor you know I’m sort of – I make music, got a family, but when I’m on that machine I’m just part of it to be dealt with and you feel tethered to it. You lose your identity.

Thus being attached to the kidney machine seems for Carole to have come to symbolize her becoming part of the bigger machine – the hospital regime. And Carole is explicit in pointing to how the institutional routine serves to undermine her identity. When dialysing, rather than being the person with multiple roles – mother, partner, artist – she perceives herself as becoming a patient, ‘just something to be taken off the machine’. The use of ‘tethered’ continues the suggestion of a convict or trapped animal.
Carole suggests interaction with hospital staff only increases the process:

You’re up there like three times a week and you see the same nurses and so on and see the same other patients and there’s only so far you can go with that relationship. But you’re seeing them so often and yet it’s always on this sort of ‘Hello how are you today?’ and sort of ‘Oh well not all that’. ‘Right you’re on that machine’ and you know (laughs) and you think oh here we go again it’s – yeah get’s sort of tedious really ‘cos I suppose the – because the relationship or the experience doesn’t deepen in any way.

Carole is frustrated by the discrepancy between the frequency of interaction and its superficial quality. Although Carole must spend a great deal of time at the hospital the relationship there fails to address her as a person with multiple roles and a full life outside. This is particularly marked because of the unusual nature of the situation. In one sense the nurses (and other patients) have, through the treatment, a considerable degree of physical intimacy with Carole. One does usually associate such familiarity with mutual and progressive disclosure within a close relationship.

Carole is able to put herself in the shoes of the staff and articulates some of the factors which she believes lead to such superficial exchanges:

It’s that jokey way of treating patients sort of to keep you on – there’s some sort of level. [ ] They see lots of nasty things [ ] I suppose there’s got to be maybe a standing back as well and protecting themselves throughout the day.

However recognition of the protective motivation, both towards self and towards patients, which may be prompting the perceived detachment, does not lessen the alienation Carole feels.

Carole is therefore trapped spatially, temporally and institutionally and perceives herself as having no control over the situation:

I just hate that being out of control [ ] It’s like being tethered to the situation (laughs) and not having the power to change it or to be perhaps a part of it. You just play your part which is quite a passive one and erm get on with it really.

So Carole sees herself as being both part of, and not part of, the system. Although she feels as though she is part of the hospital machine, she also feels detached from both the workings, community and management of that machine, rather perhaps like an outsider who intrudes occasionally. The net result appears to be induced and self-reinforced passivity:

It makes you a little bit more passive in that when you come in you think right that’s my place and I’ll get on with it. You wait till you’re told which one to go to and it’s a bit like ‘you’re over there’ (laughs) so you go and get yourself settled.
'It's waiting to hurt me'. Carole appears to project her current trepidation about dialysis onto the machine itself:

**Interviewer**: How do you think of the machine?

**Carole**: I think I find it quite harsh. It's stuck up there or down there I think it's sort of waiting for me (laughs) waiting to hurt maybe and keeping me prisoner to it.

A presentation of the machine as malevolent seems to symbolize the entrapment Carole feels. Her sense of passivity and helplessness are turned, in the account, to her being a victim of the machine. Furthermore, while recognizing the good the dialysis machine is doing her, Carole is acutely aware of its invasive nature:

It's sort of intrusive cos it's got these sharp needles of the thing that a Haches you to it [] with the needling [] It can be quite painful and it's yeah that intrusion of metal into a very soft part of yourself.

And the needling is aversive not just because it is painful but because of the very real effect it is having on Carole's body:

The arm is changing all the time now the veins are getting bigger and it's getting a bit sorer and it bruises and so you know you've got this part of you that's being um deformed.

Thus, as well as operating at the level of Carole's perception of the social and psychological impact on her, the assault on self is also more literal, manifested physically as Carole witnesses the negative impact of dialysis on part of her body.

Paradoxically, although the machine can be personified as evil, it is also characterized as impersonal. Thus, mirroring the superficial exchanges with the nursing staff, the connection with the machine remains detached:

**Interviewer**: I got the impression you don't necessarily know which one you'll be on? []

**Carole**: No and it's not always in the same place either. [] You wait till you're told which one to go to.[] I mean I don't mind in different places particularly but it's just coming on to the ward I suppose yeah maybe it would be nice if it was the same one yeah maybe that would be good psychologically.

'When I get it home and it's mine'. The intention is for Carole to transfer to home dialysis some time in the near future and during the interview she alludes to this future a number of times. Much of Carole's view of home dialysis produces a symmetry with her description of hospital treatment and is clearly therefore also a commentary on the current regime. Looking ahead to the difference home dialysis will make, Carole says:
Again Carole points, unprompted, to the degree to which hospital dialysis undermines her sense of identity. She thinks that once she begins dialysing at home it will become more incorporated into her everyday life, transformed from hospital ritual to ‘just ... some treatment’. Thus as the centrality of treatment fades, so Carole’s sense of being a person separate from a dialysis patient can be foregrounded once more. Again Carole’s views of dialysis are captured in how she talks of the machine:

"I think when I get it home and it’s mine and I get it on my own premises and it’s a part of my life and put it’s place it’s little back room then I think yeah it’s under my control and I use it."

Ownership, place and control are intimately linked. Rather than Carole having to enter the machine’s territory – the hospital, the machine will be installed in Carole’s home and will become hers. Consequently the machine (and dialysis) will be relegated to its subordinate status, as it is ‘put in its place’. Carole clearly perceives the greater control this will bring her as being a crucial element in asserting her sense of identity. And the assertion of self, and the establishment of agency, is manifested in the resurgence of the active voice in these extracts contrasted with the predominant passive in much of her description of hospital treatment. Carole is clearly looking forward to a time when she perceives herself as being able to take control of her life again.

A further advantage she perceives with the move to home treatment is more flexibility:

"I’m not having to go through all this rigmarole of hospitals and all that it entails. [] I can come to it when I want you know when the time I think oh in the evening time right I think I’m ready to dialyse now. [] So yeah that’s flexible, so you can actually fit things around or the dialysis fits around you."

Thus temporal flexibility also has implications for personal control and agency. Whereas in hospital the person is fitted into an externally controlled schedule, at home ‘the dialysis fits around you’.

Finally, dialysing at home will let her to get to know the machine on her own terms.

**Carole:** I think it would become more user friendly, that it would be my machine and I’d clean it down and maybe get to know it a bit better.

**Interviewer:** What would that mean?

**Carole:** I think it would mean that I’m not dominated by it. [] Have a bit of poke around and see what this and that is.[ ] As long as you’re in sort of total control then it’ll be better.
This suggests part of the reason Carole feels intimidated by hospital dialysis is her lack of knowledge of the equipment and its workings. At present she is dependent on the staff who operate the machine and her lack of knowledge disempowers her. Once she is dialysing at home, her sense of personal control can also be enhanced by greater knowledge of, and responsibility for, the process.

‘Idreamt about the devil’. It is clear from her responses in the interview that Carole is concerned about how dialysis treatment is affecting her and the cumulative account suggests that the impact on self is a particularly important construct for her. Final evidence for the pervasive nature of Carole’s concern is suggested by her recounting the following dream:

I’d dreamt about the devil that was my latest real bad nightmare where my husband had to wake me up ‘cos I was um whimpering he said and I was in a room with my Mum [] clinging to one another in a room, small room and my name being called by this um nasty spirit outside the room. And then it would suddenly rush in through the walls and then through my body and out the other side and when it rushed through it was like a nervous um an electric shock. And it was very painful this sort of rushing through. And then it would call my name again sort of very quietly I thought I was safe and it would call – I knew it was going to happen again.

Now consider the parallels between Carole’s dream and her experience of dialysis. Box 7.2 shows the text of the dream on the left side, alongside extracts from Carole’s account of dialysis but sequenced to enable comparison with the dream.

<table>
<thead>
<tr>
<th>Box 7.2  Dream and dialysis</th>
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<tr>
<td><strong>The dream</strong></td>
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<td>I’d dreamt about the devil that was my latest real bad nightmare where my husband had to wake me up ‘cos I was um whimpering he said and I was in a room with my Mum [] clinging to one another in a room, small room and my name being called by this um nasty spirit outside the room. And then it would suddenly rush in through the walls and then through my body and out the other side and when it rushed through it was like a nervous um an electric shock. And it was very painful</td>
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The parallels are so striking that a reasonable interpretation seems to be that
the dream symbolizes Carole’s perception of dialysis, pointing to just how
extensively dialysis pervades her thinking. She isn’t even able to escape it
when asleep at night. And the symbolism of the dream serves to highlight how
devastating the impact of dialysis treatment is for Clare.

Summary

What clearly emerges from the data is the way in which Carole feels her sense
of identity is being undermined by the treatment. She discusses the spatial and
temporal restrictions imposed by the dialysis regimen and how this is trans-
formed, through her perception of the institutionalization to an invasion of
self. Thus she seems to consider that her sense of being a person with a set of
roles and activities in her life becomes lost in the hospital situation. Carole also
feels she has no control over this process. Carole’s perception of the invasive
nature of the regime is symbolized by her account of the machine itself which
is described as both malevolent and impersonal. Carole looks forward to
dialysing at home, which she feels will allow the reestablishment of her sense
of identity, as the machine becomes incorporated into her everyday life, and
she retakes control.

Discussion

Charmaz (1983, 1995) has written extensively about the relationship between
chronic illness and the self. Her 1983 paper is based on a study of chronically
ill people with a range of different conditions, and she suggests a number of
sources of suffering can be discerned in the patients: (i) living the restricted
life imposed by chronic illness is perceived to undermine autonomy; (ii) per-
sons with chronic illness receive various discrediting definitions of self; for
example, from being talked down to; and (iii) chronically ill people feel they
are becoming a burden as they lose their ability to control their life in the way
they are used to and had hoped to continue. Charmaz theorizes these sources
of suffering in terms of a loss of self.

Charmaz’s work provides an important context for the existing study. Her
methodology is consonant with this project; she conducted semi-structured
interviews with patients but employed grounded theory to analyse the material.
The study presented here is able to complement the work of Charmaz by providing an even more detailed picture of how some perceived ‘sources of suffering’ can lead to a loss of self for this particular person. Thus we have seen how Carole describes the effects of temporal and spatial restrictions and their institutional contextualization on her sense of identity and how she perceives herself to have little control over her situation. Qualitative research can valuably make a two pronged contribution to the psychology of chronic illness by documenting detailed processes occurring in particular individuals and by discerning patterns at the broader level within different patient groups.

Dialysis treatment has, for Carole, come to mean restriction, entrapment, lack of control, passivity, invasion, fear. These are not descriptions of the treatment itself, but rather of how Carole construes the meaning of the treatment for her at this stage in time. And it is these particular constructions that play into the undermining of her sense of identity that Carole experiences. Other constructions may be, and are likely to be, different – perceptions of other patients or perceptions of Carole at other times. Indeed she suggests she had a more positive view of dialysis when it began and looks forward to a more positive conception in the future when she begins home dialysis.

This emphasis on the individual making sense of their health predicament points to the possibility of a fertile dialogue with quantitative models in health psychology. Sense-making is crucial to how we have framed Carole’s experience of her treatment and it is also central to many of the models used by health psychologists to examine individuals’ behaviours. Therefore mixed methods studies combining quantitative instruments like the illness perception questionnaire (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002), and in-depth experiential qualitative methods like IPA, could lead to an enhanced understanding of individuals’ reactions to changing health status. See Smith (1996) and Chapter 12 where this potential relationship is discussed more fully.

What implications does this study have for practice? First, a note of caution. This is the case study of only one woman, and, as stressed at the outset, it is not argued that she is necessarily representative. However, the strength of the control construct for Carole and its prominence in the literature, both generally and with regard to dialysis, suggests one can perhaps look to possible implications of the study.

Certainly for Carole the re-establishment of a sense of personal control is a priority and she perceives that this will be facilitated by her change to home dialysis. However, not all patients can dialyse at home and nor is that the point of making this observation. It is quite possible that different individuals will perceive control and how to gain it in different ways. Thus it is important to take heed of individual accounts in order to determine effective intervention. As Kirschenbaum (1991) points out there are various ways hospital dialysis treatment could be modified to make the patient feel more involved and more in control. One could speculate, for example, that were Carole to continue...
with hospital dialysis, providing her with a greater understanding of the machine’s workings and including her more in the physical tasks involved would enhance her sense of control. Consistent with the thrust of this study, we would urge that when considering interventions or changes, two things are emphasized, firstly that it is the patient’s perception of control which is important rather than control *per se* and, secondly, that individual perceptions of what can enhance control will vary so that the patients should be closely involved in discussions of possible changes that could be made.

Thinking about where to go next with this study, there are a number of possibilities. Playing to the strength of its idiographic potential, it would be interesting to follow Carole through time and see how her experience changes, particularly once she starts home dialysis – comparing this with her expectations. An alternative would be to include an ethnographic arm, observing what happens on the ward and possibly talking to the health professionals about their perspective on caring for Carole.

We would hope the reader can see the value of a detailed case study such as that presented here in helping to understand what it is like to have a major personal experience. We would also hope that the reader, even though they may not share the content of the experience of Carole, nevertheless feels a resonance with the way it impacts on her existentially. We would concur with Warnock (1987) in arguing it is the very detail of Carole’s case which allows for this potential for an understanding of a shared humanity.

The case also provides a good example of some of the elements of hermeneutics outlined in Chapter 2. First it illustrates Heidegger’s appearance. At one level, Carole’s dream is not about dialysis at all. And yet equally one can say it is all about dialysis. Therefore, the phenomenological importance of the dream is suggested by the manifest content but its latent force appears or comes to the fore during the process of analysis. By establishing a trusting and intense research relationship with the participant, the interviewer has been able to facilitate her disclosing personal material which can then be interpreted to help deepen our understanding of the phenomenon.

We can also see the dream acting as a ‘part’ to the ‘whole’ of the case study. The dream sequence is powerful in its own right but its meaning is strengthened when one recognizes it as contributing to the whole – the understanding of the personally debilitating impact of dialysis for Carole. And of course the horror of the dream becomes even more vivid when one realizes that much of what it seems to be about is the dialysis treatment.

**Other research on health and illness**

Health psychology is the area of psychology where IPA first became established (see Brocki and Wearden (2006) for a review). Therefore there are now a considerable number of studies examining, for example, the patient’s personal
experience of particular conditions, treatments and decision-making. There are also studies exploring the perspective of the carer and the health professional. This section will present short summaries of some of these studies to give a flavour of the work which has been done. Reference will also be made to other related studies.

**The experience of chronic fatigue syndrome**

Arroll and Senior (2008) conducted interviews with eight people who had had chronic fatigue syndrome for many years, in order to learn about their experience of the condition. The interviews were analysed with IPA. The paper usefully illustrates the shared themes of the respondents but also the particularity of individuals’ experiences. The paper is constructed in terms of the illness trajectory – from initial experience of symptoms to diagnosis and treatment.

Participants describe the complex patterning of symptoms. As part of this, Gerald points to the lack of precision in the term used for the condition:

> The thing that really spoils your life is what I call lack of stamina. I don’t like this concept of chronic fatigue, I’m not tired all the time, sometimes I’m not tired at all. If I do nothing I often feel pretty well, as soon as I start doing something it tired me too quickly. (Arroll & Senior, 2008: 448)

The paper also captures the difficult process of trying to make sense of the problem, for example assessing the symptoms and considering them in relation to possible causes:

> When I first became ill, I wasn’t sure it was ME and I was overseas […] I think I had gut problems initially but of course in the less developed countries there are those things around, parasites and other bits of stuff so I think my weak area for a while had been the gut which of course doesn’t give you much energy and its sore so I suppose for a while I thought that was the main issue and it may have been to begin with. (p. 450–1)

This is followed by a careful examination of participants’ descriptions of the problems involved in obtaining a medical diagnosis for their condition.

For other examples of studies on the personal experience of serious health conditions, see these papers on: bone marrow transplantation (Holmes, Coyle & Thomson, 1997); chronic back pain (Smith and Osborn, 2007); multiple sclerosis (Borkoles et al., 2008; Reynolds & Prior, 2003), osteo-arthritis (Turner et al., 2002); spinal cord injury (Dickson, Allan, & O’Carroll, 2008); vitiligo (Thompson, Kent, & Smith, 2002).

**Deciding whether to attend a cardiac rehabilitation programme**

A significant part of the process of dealing with illness is decision making on the part of patients and professionals. Wyer, Earll, Joseph and Harrison (2001)
investigated factors influencing whether people who had had a heart attack attended a cardiac rehabilitation programme aimed at helping participants with exercise, lifestyle and stress management. Semi-structured interviews were conducted with nine attenders and 12 non-attenders and the researchers compared participants’ responses in relation to components of Leventhal’s self regulation model of health behaviour. Thus the paper is an interesting example of IPA working closely with quantitative models in health psychology. Attenders and non-attenders differed in a number of ways. For example, attenders typically had a more psychological model of health and illness while non-attenders tended to have a more medical model:

I think you can make yourself well. You just have to get on with it. You’ve got to be positive. (attender, psychological model) (Wyer et al., 2001: 181)

I rely on the doctors and nurses to look after you. It’s their job to look after my health. (non-attender, medical model) (p. 182)

Similarly the paper illustrates differences between the groups in terms of their coping style with attenders displaying approach coping, non-attenders avoidance coping:

I want to get better and I want to do everything right. I’d rather someone who’s got more knowledge told me what to do. (attender, approach coping) (p. 183)

I didn’t ask anything. It’s better to let the body carry on with it. You’re better off not knowing. (non-attender, avoidant coping) (p. 183)

Wyer et al. are able to use these differential responses to construct a model of the decision making process in patients. Other IPA papers on decision making in health are Daniel, Kent, Binney and Pagdin (2005) on the decision making in families where elective surgery for short stature is available for their children, and Smith, Michie, Stephenson and Quarrell (2002) considering the decision making process for the genetic test for Huntington’s disease.

The psychology of being a carer

Most IPA research in health has examined the personal lived experience of the patient. This is not surprising as it represents the core concern for a phenomenology of health and illness. However, illness has a broader relational and social context and it is also important to explore the personal experience of carers. Hunt and Smith (2004) conducted detailed semi-structured interviews with four carers of recent stroke survivors. Interviews were conducted while the patient was still in hospital. Each of the carers was the family member who would take primary responsibility for the patient on release from hospital. Three super-ordinate themes emerged during the analysis: uncertainty, personal impact, strength of relationships. There was a pervasive sense of uncertainty in
participants’ accounts as they tried to make sense of what was happening to their parent or spouse. Carers were clearly deeply concerned for their loved one but then went on to discuss the way in which the situation was affecting them personally. Carers felt tired, stretched and under pressure to attend:

I don’t like to neglect him ‘cos if I do I feel, I don’t want to, I do feel guilty. I don’t, I shouldn’t feel guilty. I think, ah, he’s got no one visiting him. (Hunt & Smith, 2004: 1005)

Three of the four carers describe being within a nexus of close relationships within their family, both with the patient and with others:

I’ll do anything for her and I don’t mind either, if it’s going to make her happy and it makes me happy. (p. 1007)

We have been a very close brother and sister, we always have been [ ] even before my mum had a stroke we always spoke on the phone every day. (p. 1007)

The strength of the relationships offers support to the carers but can itself sometimes become a source of tensions. The findings are related to other studies on carers in the literature. A related paper is by Glasscoe and Smith (2008) on the parental experience of caring for a child with cystic fibrosis.