

# **Narrative as a resource in accounts of the experience of illness**

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## **Introduction**

The stories we tell about our everyday lives are an important resource for making sense of our experiences. Through narrative we structure and interpret our experiences (Labov and Fanshel 1977), create coherence in our personal life stories (Linde 1993), construct, display and reinforce our sense of self (Schiffrin 1996), and relate this sense of self to others in our social worlds (Bruner 1986). It is not surprising that narratives have been found to occur in a wide range of contexts, both public and private, from family dinner times to courts of law. In this paper we focus on the narratives that occur when people talk about their experience of illness during an interview with a researcher. Our specific concern here is not with an illness construed as a single bounded event (such as, for example, appendicitis or pneumonia) but with a chronic condition (hypertension) that becomes a permanent part of an individual's life. Hypertension is not a disease, as such, but a major risk factor for heart disease and stroke. People with hypertension need to have life-long medication to reduce this risk. We wish to examine the stories individuals tell as they talk about their experiences of the condition, to see how, through their narratives, they integrate the experience of living with hypertension into their life story and make the everyday details of coping with hypertension part of their sense of the kind of person they believe themselves to be.

## **DIPEX: a database of individual patients' experiences of illness**

Our data come from a series of interviews carried out by Sue Ziebland for a website resource on hypertension as part of [www.dipex.org](http://www.dipex.org) (DIPEX: personal experiences of health and illness, described briefly below, and more fully in Herxheimer et al 2000). DIPEX is the initiative of a team of medical practitioners and social scientists. Briefly, the overall aim is to provide a more patient-centred perspective on illness, which will serve as a resource for patients and their carers, and for health care professionals. Each module on the web site deals with a different health problem and is developed as a stand alone qualitative study of patients' experiences. Semi-structured interviews are carried out with a maximum variation sample of 30-50 patients from different social backgrounds throughout the UK. The interviews are then used to identify issues that are important to patients. The range of conditions covered by DIPEX is increasing rapidly: in 2003 [www.dipex.org](http://www.dipex.org) included modules on hypertension, cancers of the lung, prostate, breast, bowel, testes and cervix, cervical screening and epilepsy. Work is in progress on many more.

For patients, the DIPEX website is the main resource. Each illness module has summaries of the main themes emerging from the interviews, with illustrations from video, audio and written clips. It also contains descriptions of the condition, details of its prevalence and its prevention; information about treatments; and questions and answers. There are

links to other relevant websites, including support groups and voluntary organisations. The website thus acts as a reference point for patients and their carers, where they can find out about the experiences of others as well as accessing more conventional health information. For health care professionals DIPEX presents a patient-centred perspective on a range of illnesses with the aim of enabling good communication between patients and professionals. It also provides an educational resource for medical and nursing students, which can also be used for postgraduate and in-service training.

Although the website necessarily contains only short clips from the interviews, there is a wealth of information in the full transcripts about how patients have reacted to their condition and how it has affected their lives. The transcripts have been used for qualitative analysis of a range of issues (see, for example, Chapple and Ziebland 2002, Chapple et al 2002, Rozmovits and Ziebland in press) and further studies are in progress. This paper, however, is the first to explore the potential of the transcripts for furthering our understanding of sociolinguistic and discourse-analytic questions. Mischler (1986) points out that narratives occur frequently during interviews if those being interviewed are given room to speak. This is what we found here: many patients responded to the interviewer's questions with narratives, although some individuals, of course, related more stories than others. As we said in the Introduction, we focus here on the interviews carried out with individuals diagnosed with hypertension. In particular, we will examine the narratives told by two individuals, referring to them as Rose and Josephine.

### **Rose and Josephine**

We chose these interviews for detailed analysis because there were some broad similarities in the medical histories of the two women. They had been diagnosed at about the same age – when they were in their mid-twenties – and both had been living with hypertension for many years: Rose was 72 at the time of her interview, and Josephine was 53. In addition, they each suffered from other serious illnesses that had a continuing effect on their everyday lives. Rose had a form of epilepsy that caused convulsions while she was sleeping, and throughout her life she had experienced severe migraine attacks. She had recently been hospitalised because of three “mini strokes”, and she often collapsed and fell down. Josephine’s medical history was more dramatic still. In her early thirties she was admitted to intensive care when her extremely high blood pressure caused heart and renal failure. Five years later she received a kidney transplant. As a result her health was under constant supervision, requiring regular attendance at hospital outpatient clinics. Both women had to take medication every day of their lives.

Despite the similarities in their medical histories, Rose and Josephine had very different reactions to the experience of living with chronic illness. They gave a first indication of in their answers to a question put to them early in the interview: “do you have an image of the sort of person who might have high blood pressure?”. Rose unhesitatingly replied “yes, someone like myself” (indicated by the arrow in extract (1) below) and went on to relate her reply to an aspect of her personality (her tendency to rush), as we see.

(1) Sue:           do you have an image of the sort of person who might have high blood pressure?

→Rose: yes someone like myself <LAUGHS>  
 Sue: right and how would you =  
 Rose: = someone that rushed about everywhere and er I'm not a bit highly strung.. I wouldn't say that but I'm a real rusher...er I've only recently slowed down because I fractured my arm and done things to myself that I thought well it's because I'm rushing that I'm falling you see

Rose seems to be, then, a person who has no problem seeing her illness as a part of her personal identity. She attributes her recent falls not to her medical condition but to her personality – to the kind of person she believes herself to be.

Josephine, by contrast, presents herself as an atypical example of a person with high blood pressure, saying that such a person would be “not like me” (it is relevant to note that she is slim and no longer smokes):

(2) Sue: do you have an image of the sort of person who would have high blood pressure?  
 Josephine: well er I think smokers could be... I mean as soon as you say an image I see a large red-faced man .. probably with a fag on...certainly with a big beer belly  
 → who is always going to go on the diet tomorrow and so on ...not like me

Josephine explains later in the interview that she actively distances herself from her experiences of illness, seeing them as not experienced by “the real me”. She describes in (3), a non-narrative passage, how her friends and family know her as 'Jo' or 'Josie' whereas she presents herself to health care professionals as 'Josephine':

(3) er I have a way of dealing with it ... I don't consider myself ill or an invalid but I know I'm going to need treatment for the rest of my life...and in a way it's not happening to me it's happening to someone called Josephine Smith...nobody at the hospital knows that I'm not called Josephine by my friends and people who know me so when I go there then it's her...it's Josephine that's being looked after and treated and is having to waste time on this stuff... I've felt for a long time now that the real me is a kind of observer of this and so it doesn't get to me...and Josephine Smith takes care of all that side of it and does all that's required and meanwhile the real me ...I'm getting on with the rest of my life

Rose and Josephine, then, seem to have very different strategies for making sense of their experiences of illness, and it is for this reason that we focus on the stories they tell within their interviews. We will see that despite their different reactions to their condition each of them uses narrative to structure their experiences in such a way that they are integrated coherently into their life story and their sense of personal identity.

### **Defining narrative**

We have worked with the classic definition of a narrative unit, taken from Labov and Waletzky's (1967) framework. Thus a narrative, for us, contains at least two Complicating Action clauses where the verbs are in the past or historic present tense, and where we can infer that the order of the clauses matches the order in which the recounted events took place. There are also one or more Orientation clauses setting out who was involved in the events, when and where the events took place, and giving other necessary

background information. In the DIPEX interviews an initial Abstract, summarising the story, is often provided by the interviewer's question. The Complicating Action section is followed by one or more clauses giving the Resolution of the story; and the narrative sometimes ends with a Coda that returns us from the story world to the present.

These sections of the narrative constitute the referential or propositional strand of meaning. They recount the facts of the story – without them there would be no story. However, narratives also have an affective strand of meaning where narrators reveal their feelings about the events they are accounting. This is equally essential to the narrative, justifying the telling and, importantly for our interests here, showing the kind of person the speaker claims to be: "narrative is a presentation of the self, and the evaluative component in particular establishes the kind of self that is presented" (Linde 1993: 81). The affective strand may be expressed in separate Evaluation clauses, but evaluation may also occur through the use of intensifiers and other linguistic forms within the clauses constituting the referential strand (see further Labov and Waletzky 1967, Labov 1972).

## **Rose**

### *Classic narrative forms*

Rose tells more stories than any of the other patients in the hypertension section of the database: eighteen stretches of discourse correspond to the definition of narrative outlined above, including some where the form is slightly modified, as we will see. In some of these narratives Rose's close integration of the referential and affective strands serves as a clear example of the way speakers can use narrative to integrate their experiences of illness into a coherent sense of their personal identity. We illustrate this with her account of her first experience of hypertension, in (4).

- (4) Sue: So I wonder if I could just start by asking you to tell me how you originally discovered that you had high blood pressure?
- Rose: 1. Yes well at the time I was 26 years old  
2. I was pregnant with my daughter Gillian  
3. and er I had.. I was told by the doctor that I had to go to bed  
4. this was about 4 weeks before she was delivered  
5. and I couldn't understand it at the time I must admit  
6. and he said that he would sort it out afterwards  
7. er however I did go to bed for 4 weeks before she was born  
8. and er and then er I got up a couple of times whilst I was in bed  
9. I was a bit naughty
- Sue: right <LAUGHS>
- Rose: 10. and I got up  
11. and er when he came in to take my blood pressure  
12. he found that it had gone sky high  
13. and was very concerned  
14. "if you don't stay there" he said  
15. "well you'll have to go in hospital"  
16. so I stayed there  
17. and then er and then she was born within 4 weeks after that

18. er and my blood pressure still stayed high

19. so that was the first time I ever came in contact with.. with blood pressure

In the referential strand of her story Rose has selected relevant factual aspects of her first experience of hypertension to produce a chronological account that answers the interviewer's question; but her story accomplishes more than this. For example, her evaluative clauses connect her subjective state in the story world she is constructing to her present attitude to her illness. Thus in line 5 the evaluation clause *I couldn't understand it at the time* is syntactically dependent on the present tense clause *I must admit*, indicating that from her present perspective she does now understand why she had been told to go to bed. Secondly, the evaluation clause *I was a bit naughty* in line 9 displays a characteristic of her personality that she also mentions later in the interview (as we will see in the following section). In this way her account helps to construct what Rose appears to see as a stable aspect of her personal identity. Thirdly, she uses embedded external evaluation in the clauses in lines 14 and 15 to portray, through the doctor's concern, her dawning realisation that her high blood pressure was a serious condition; and she uses internal evaluation, with the choice of the adjective *sky-high*, to dramatise her blood pressure. By telling her story in this classic narrative form, then, Rose creates coherence not only through her representation of the sequence of the factual events but also through the sequencing of her subjective experience of these events. Rose's account of her first encounter with the illness that has been since been a constant part of her life makes sense of the experience both objectively and subjectively; and she expresses within her account of that experience what for her is a salient aspect of her personal identity.

### *Habitual narratives*

In classic narratives the verbs recounting the actions are in the simple past tense or historic present tense, allowing the events to be represented as a 'blow by blow' sequence. However, Rose tells several narratives where the verb phrases involve the auxiliaries *used to* or *would*. Extract (5) is an example of one such habitual narrative. As before, the interviewer's question can be analysed as the abstract. We indicate with an arrow the lines where the verbs express habitual aspect.

- (5) Sue: have you ever.. for your blood pressure have you ever used one of these self monitors, these  
Rose: no I've always  
my brother in law.. my brother in law had one  
but he annoyed me in a way  
→ because he used to keep taking his blood pressure every...  
it was like a toy for a bit you know  
I mean he doesn't do it now but he did at the time  
→ and er I used to think "there's no wonder he's got blood pressure  
keep on taking it  
it's enough to give you blood pressure.. you know"  
and when he said "do you want me to take your blood pressure?"  
→ I'd say "no thank you"  
oh dear spoil sport really.

The point of Rose's story is partly that she spoilt her brother-in-law's fun. This is consistent with the aspect of her identity that she displayed in extract (4), where she presented herself as having been "a bit naughty". A further point of the story, however, is that in her opinion it is more sensible not to keep thinking about your blood pressure; and that this is how she herself lives her life. This too is consistent with the kind of person she presents herself as being, as we see in (6):

- (6) Sue: OK.. do you think of yourself as somebody who has high blood pressure?  
Rose: no no I don't even think of it.. I just take my tablets and do as I'm told  
Sue: you don't think about it normally?  
Rose: I'm not a worrier in that respect...when people say they've got...they're worrying about this and to me that's so small to worry about but people do I know.. I know people do worry yes it's a natural thing to do

Habitual narratives are a less dramatic style of narration, since they cannot reproduce the blow-by-blow effect of a story about a single occasion. Instead, they tell of the general course of events over a period of time, with the verb forms and adverbs marking repetition and routinization (Riessman 1990: 1197). In Rose's narrative the habitual forms allow her to bring together in a single clause a repeated series of reactions to her brother-in-law's behaviour, showing how she consistently adopts a behaviour she believes to be more sensible than his. Riessman's analysis of the narratives told during an interview with a man living with advanced multiple sclerosis also notes a large number of habitual narratives. Perhaps these are likely to occur in talk about the experience of chronic illness because that experience inevitably includes a series of repeated events and everyday small decisions about the management of the illness. In any case, here the verb forms used within the narrative make it possible for Rose to display aspects of her identity that she elsewhere claims for herself (the fact that she is "not a worrier" and that she is sometimes "a bit naughty"), and to show that these aspects of her self identity are constantly reinforced through the repeated events that she recounts in her narrative.

### *Comparison with others*

The narrative in extract (6) illustrates a further characteristic of Rose's stories, many of which relate incidents where other people with the same condition as Rose behave in a less competent way than Rose herself. In (6), as we have seen, Rose contrasts her own behaviour with that of her brother-in-law. In the narrative in (7) the comparison is with her neighbour. Mention of the neighbour triggers a short narrative illustrating the sensible system Rose has adopted to ensure that she does not forget to take her medication. The beginning of the narrative is indicated by the arrow.

- (7) Sue: now do you ever find that you forget to take your medication for blood pressure?  
Rose: no.. no I don't...the reason being that little blue box over there on the table...underneath that top thing.. that has.. that is done every week er for 7 days  
Sue: OK  
Rose: so I've only got to go to that and if I found... which I never have.. if I found that they were still there I would think "oh I've forgotten today"...but I've never had that problem  
Sue: right so that's your way of making sure that you're taking them?  
Rose: yes, and I put them out from there into a little jar every morning so that they go from there to there and then into me, so it's a sort of way that I work it

→ because my neighbour said "I forgot the other day"  
well I don't think I'd get far if I did forget  
because I only once walked out of this house going up to the bus stop  
and I felt my heart was beating like a drum  
and I felt "oh no I bet I've forgotten my tablets"  
and I came back  
and they were still in the little jar  
so yes I would know.

Social identities become meaningful when we compare the behaviour of our own social group with that of other groups (Tajfel 1974, 1981). Telling stories is a way for us to locate our selves within the group to which we feel we belong, recreating the perspectives these groups have on their lives. Personal identities, similarly, are created by comparing ourselves with other people, and again we can locate ourselves as an individual through the stories we tell. This time, however, the comparison is often with people in the same social group as ourselves. It is instructive, then, to note that in her stories Rose compares her own experiences of coping with hypertension with those of other people with the same condition, and that she depicts herself as managing her condition better than they do. By locating an identity within a group of people who have the same illness as herself, Rose accepts her condition. Furthermore, by comparing her behaviour favourably with others in the group she is able to construct a positive identity for herself whilst detailing the everyday details of living with the condition. The identity she constructs in this way is in harmony with what she believes to be salient aspects of her personality, as we have seen. The story told in extract (7) provides a further illustration: here Rose portrays herself as managing her illness competently by developing a sensible system that allows her to know whether or not she has forgotten her pills. Her competence accords with what she says about herself in a non-narrative stretch of discourse, in (8):

(8) I like to be in control of myself and not being in control wouldn't go down very well with me ..I know it wouldn't ..you know what I mean?

Rose's accounts of her everyday experiences of illness, then, are presented through the lens of what to her are integral aspects of her personal identity. In this way her narratives can function in the way that Riessman (1990) has described, healing discontinuities between a person's idealised sense of who they are and the restrictions that an illness imposes on what a person can do and the kind of person they can be in reality. Rose cannot, in fact, always be in control of herself: as mentioned earlier, she has epilepsy, she has suffered three small strokes, and she falls down frequently. Some of her narratives, then, are enclaves where she creates a self that is in harmony with her ideal self (again, see Riessman 1990).

Because *narratives*

Interestingly, five of Rose's eighteen narratives are introduced with *because*, a story opener that has not been much commented on by other researchers. One example is shown by extract (7) above; a further, more complex example is given in (9). The start of the narrative is indicated by the arrow.

(9)	Sue:	has anybody ever mentioned er cutting down on salt?	1
	Rose:	well yes but I read about Tracidrex.. it says on the packet "do not cut down"..	2
		meaning "do not cut down on salt" because this property.. this Tracidrex takes it	3
		out of your body...I don't think many people know that	4
	Sue:	right	5
	Rose:	and er so therefore it says you know don't.. meaning don't cut the salt out..	6
		it doesn't say "don't cut it down" but "don't cut it out"	7
	Sue:	OK	8
	Rose:	because you can get low on sodium? I think it's sodium..well sodium is salt I	9
		think so you can become low on that... er so er no I don't cut down..I don't have	10
		as much as I used to	11
	Sue:	and did anyone point that out to you or do you read that in ??	12
	Rose:	no I read everything, I read all the little bits, all the inner nooks and crannies	13
		and I find out myself you know	14
	→	because my sister said to me er er "do you cook with salt?"	15
		and I said "yes I do, I put a little bit in"	16
		she says "well you know you've got blood pressure"	17
		and I said to her "well my"	18
		I says "I'll give it to you to show you"	19
		and I showed it to her	20
		and she said "oh I haven't read that"	21
		I said "well you don't take Tracidrex	22
		but you should be reading what's in yours or what you should be doing	23
		may be with you you shouldn't cut it out"	24
		because she's been low on sodium just lately	25
		so may be it's because she cuts out you know	26
		so that's a thing to think about	27

Here Rose again shows herself as in control, managing her illness competently; and again she creates this aspect of her personal identity by contrasting her own behaviour with that of another person with hypertension, this time her sister. *Because* clauses occur frequently in conversation, presumably because of their semantic role of explaining the speaker's thoughts, feelings or actions (Biber et al 1999: 841). As a narrative opener Rose's *because* retains its basic meaning, indicating that the story that follows will provide a justification to explain the assertion she has just made. She claims, in line 14, that she found out for herself that she should not cut down on her salt intake, by reading the information that came with her medication. The *because* narrative then justifies this assertion by giving a specific example of an occasion when Rose showed her sister her information leaflet, demonstrating that she had indeed read it. It also, however, justifies the assertion made earlier, in line 4, where Rose claims that not many people know, despite conventional medical advice to the contrary, that some specific anti-hypertensive medication should not be combined with reduced salt intake. The *because* narrative justifies this assertion too, by providing the example of one such person who did not know this (her sister). Thus the narrative presents Rose as a person who stays in control of her health (by informing herself about the management of her illness) not only in contrast to her sister, but also in contrast to most other people who take that medication.

The narrative introduced by *because* in (7) similarly provides a justification for Rose's assertion *I don't think I'd get far if I forgot*, recounting one such occasion when she did forget and when she did not get far from her home. In both these examples, then, the *because* narrative justifies the assertions Rose makes about her own attitude to her

condition compared to other people's attitudes, and provides a further opportunity for her to present her own behaviour in a positive light, showing how competently she manages the everyday details of living with hypertension.

### *Reported speech*

Like most of the patients interviewed, Rose, often reports on her interactions with doctors and other health care professionals. This is not surprising, given the salience of these interactions in the experience of serious illness, for it is during such interactions that decisions are made about the management of the illness and information transmitted about the nature and the progress of the condition. Interactions between patients and health care professionals play a major role in the social construction of illness, then, and they are, therefore, highly reportable. For patients, these interactions may be highly charged: a doctor, say, may have only five or ten minutes available to spend discussing a condition with an individual patient, yet for that patient the outcome of the interaction is crucially important. Rose, like other patients interviewed, shows that she is fully aware of the time constraints:

(10) Rose: I would like to know more but you see when you go to the doctor's...I've got a wonderful doctor...it isn't because he wouldn't tell me ..he would if he had the time but he hasn't got the time and I know that

It is instructive to analyse how patients report their interactions with health care professionals, both in terms of what they choose to report, and in terms of how they report it. Who is given more speech in the reported interaction: the professionals or the patient? Do narrators give both themselves and the professionals direct speech, or do they report what they say indirectly? In extract (1), for example, Rose begins by using indirect speech to report the words of the doctor who first diagnosed her high blood pressure (*I was told by the doctor that I had to go to bed*), then uses direct speech to animate him as a character in the story and to dramatise his concern (*and when he came in to take my blood pressure he ...was very concerned "if you don't stay there" he said "well you'll have to go in hospital"*).

Research on actual interactions between doctors and patients (rather than reported interactions) has found that patients behave deferentially to their doctors, tending to speak only when spoken to rather than initiating an exchange themselves. The higher status they attribute to doctors is reflected in the way that patients report their interactions: what doctors say tends to be reported in the form of direct speech whereas what the patients themselves say is more likely to be reported as indirect speech. Hamilton's (1998) study, for example, found that 60 per cent of what doctors said was reported as direct speech, but only 18 per cent of what patients said was reported in this way.

We analysed the reported speech in Rose's accounts of her interactions with health care professionals (who were mainly doctors) in both the narrative and non-narrative stretches of her interview. The results are shown in Table 1. The Table shows, firstly, that Rose reports what the doctors say more often than she reports what she herself says: of the 55

reported speech clauses, 32 are from doctors and 23 from Rose. Rose seems, then, to consider the doctors' words as more reportable and, perhaps, more important than her own. We also see, however, that she reports both what the doctors say and what she herself says almost entirely in the form of direct speech: 91 per cent of the reported speech clauses, in both cases, are represented as direct speech. There were only 5 reported speech clauses in the form of indirect speech in the entire interview.

Table 1. Direct and indirect reported speech clauses in Rose's interview

	Rose speaking	doctor speaking	total
	N (%)	N (%)	N
Indirect reported speech clauses	2 (9)	3 (9)	5
Direct reported speech clauses	21 (91)	29 (91)	50
Total reported speech clauses	23 (100)	32 (100)	55

If giving direct speech to doctors indicates that narrators see the doctors as higher in status than themselves, we must conclude that Rose portrays her encounters with health care professionals as interactions between status equals. In this way she de-medicalises the encounters, treating the doctors almost as if they were her friends. Indeed, she explicitly comments on this, in answer to a question about the 'white coat syndrome':

- (11) Sue: well there seem to be some people whose blood pressure is fairly normal most of the time ...but when a doctor or a nurse or somebody with a monitor appears in front of them [their blood pressure goes up
- Rose: [their blood pressure goes up...that never worries me.. I mean a doctor is a doctor.. I don't worry about it...only if they give me the wrong dose of something.. then I would worry but I never worry about doctors... I've seen too many of them in the past...I've seen so many... well I'm losing count but no that definitely wouldn't be me...
- I'm too friendly with them...you know I'd say "hello" I mean I do... no...but I can imagine it happening

Rose also demedicalises her encounters with health care professionals through the content of the speech that she reports. Sometimes, for example, there is friendly banter. In addition, Rose shows her doctors as treating her with courtesy and respect, making her a partner in decisions about the management of her condition, as in (10). This is in marked contrast to the patients who took part in Hamilton's (1998) research, who reported their doctors' words using direct speech that showed the doctors as callous and unsympathetic,

- (10) Sue: and do they [doctors and nurses] comment on it, do they say "it's not as low as the last time"?
- Rose: oh yes, yesterday she [the nurse] did she said "your blood pressure is up" and I said to her "oh is it" "oh" she said I said "well I'm going in to see Dr Clark anyway" so she said "well don't worry it's on the screen" or something so I said "well I'll tell him when I get in there"

well when I went in I said to him "oh I've got to tell you that my blood pressure has gone up"  
and then he dealt with that after he dealt with the other complaint.. yes.

Sue: did he take it again or did he

Rose: he took it again..yes he did  
and that's when he said to me "well you've done so well  
and you're looking so well"  
and I said "I'm fine"  
and he said "so.. what.. we won't do anything right now..  
what I will do is I'll ask you to come back about the first of May  
and I will...we will then discuss it again..  
that's if you feel happy about that"  
because he's an excellent doctor  
"if you feel happy  
and we will go through it again  
hopefully it will have gone down by then  
if it hasn't we will discuss that"  
he's excellent in that respect  
he'll always discuss something with you  
and I said "yes that's fine"  
so yes.

The representation of reported speech in Rose's narratives is a further way in which she displays and constructs a coherent sense of identity: in this extract, for example, the opening lines show Rose again presenting herself as not worrying unduly about her high blood pressure. By demedicalising her encounters with health care professionals, Rose makes her constant visits to doctors' surgeries and hospitals part of a 'normal' everyday life in which she is able to maintain her personal identity.

#### *Summary: Rose*

As we said earlier, Rose tells more narratives than any of the other patients in the hypertension section of the database. The number is not necessarily significant; but it allows us to see some of the many ways in which narrative can be used as a resource to manage an identity as a patient and to make this identity cohere with a person's sense of self. For Rose, the experience of illness is an integral part of her life, and the narratives she tells reflect this. Through the stories she tells about her experiences of living with hypertension she displays and reinforces a positive self identity, defining herself in relation to other people with the same condition. This is one way, then, of adjusting to the necessity of living with a chronic illness.

#### **Josephine**

Josephine, as we saw earlier, has a very different approach to her condition. Far from making it an integral part of her life, she has set out to ignore it as far as it is possible to do so. Unlike Rose, she does not tell many stories during her interview: there are only five stretches of speech that fit our definition of narrative. As we have said, the number of narratives that patients tell is not necessarily significant. It is nevertheless instructive to examine Josephine's five narratives, since the events she chooses to recount in narrative form and the way in which she relates them are closely connected to the strategy she has adopted for dealing with her condition.

### *The first experience of illness*

Interestingly, Josephine, like Rose, answers the question about her initial discovery of her condition by telling a narrative:

(13) Sue: I'd like to ask you to tell me how you originally discovered that you I  
had high blood pressure

Josephine:

1. right er...I was living in Australia at the time
2. and er I had applied for a scholarship in Oxford
3. er and was offered one
4. and there was a medical attached
5. and er I was then about twenty-four
6. went for the medical
7. and was told I had high blood pressure
8. and they took me in as an inpatient
9. I don't think they thought it was disastrously high
10. but it was certainly
11. for a person of my age it was deemed worthy of treatment anyway
12. so they took me into hospital
13. and sorted me out in Sydney
14. and then sent me off to Oxford with my little box of pills and a letter to  
the Radcliffe Infirmary as it was then
15. and I came under their care
16. and have been supervised one way or another ever since then
17. so that's when it was picked up

Unlike Rose, however, Josephine does not represent any of the 'blow by blow' events as a reported interaction between herself and a doctor. Instead, the events related in the Complicating Action clauses (6,7,8,12,12,14) are represented impersonally, with indefinite *they* subjects and agentless passive clauses. The Orientation clause in 4 is an existential *there* clause (*there was a medical attached*) rather than a clause where she represents herself as the subject and the actor (she could, for example, have said *I had to have a medical*). It is important not to read too much into this, of course. It could be a general characteristic of Josephine's individual speech style: yet she does not adopt this detached speech style in her other narratives, as we will see. The internal evaluation and choice of vocabulary in the narrative clauses add to the detachment by downplaying the severity of the condition (for example, *sorted me out* in line 13 and *little* in *my little box of pills* in line 14), as does the external evaluation clause *I don't think they thought it was disastrously high*. Josephine's impersonal account of the sequence of events making up the referential strand, then, is matched by the content of the affective strand, where her emotional distancing from these events is displayed. Although Josephine's past and present reactions to her illness could hardly be more different from Rose's reactions, in both narratives the two women interweave the referential and affective strands into a coherent account of the objective and subjective aspects of their first experience. Both women have made this initial experience part of their life story, and the different linguistic choices they make in recounting the experience reflects the separate ways in which they have done so.

### *Comparison with others*

Rose, as we saw, constructed aspects of her identity by comparing her behaviour with that of other people she knew who suffer from hypertension. Given Josephine's desire to see the "real me" as a person unencumbered by the details surrounding her medical condition, it is hardly surprising that when she compares herself with others the basis of the comparison is people who are well, rather than other people with hypertension. For example, she answers the interviewer's question about whether she ever forgets to take her medication by describing, in a mini hypothetical narrative, her embarrassment at the idea that she might have to mention her medication to her friends:

(14) Josephine: I always carry two or three days dosage with me wherever I go  
because you never know  
say you went out for dinner  
and someone said  
oh you know "do stay the night  
don't worry about driving home"  
it would be awful ...  
I've had to do it in the past so I make sure I don't ...  
it would be awful to say  
"well no I can't because I haven't got my tablets with me"

Two further narratives show Josephine identifying with people who are well. In extract (15), for example, she recounts her decision to stop smoking, making it clear that the decision was based not on her medical condition but on the rapport she felt with the doctor, her GP. In the clauses constituting the abstract (*I was one of the lucky ones; managed to stop easily and quickly*) she explicitly situates herself within the general group of people who have managed to stop smoking, with no reference to whether those people are well or ill:

(15) Josephine: I was one of the lucky ones  
managed to stop quite easily and quickly  
I was just having a general check up at the GP  
and I liked the GP  
she was a young woman about my own age  
and I really liked her  
and clicked with her  
and she said in an extremely unpressuring sort of way  
"oh I see you smoke"  
she said " it's probably a good idea if you didn't really...  
you know... given your history"  
and it was nothing more than that  
that was all she said  
and because I liked her  
and valued her opinion  
and because she didn't come heavy on me  
I just went home  
and stopped  
and that was that

In (16), Josephine relates her decision never to talk about her medication. Here she compares herself with her father-in-law, "still quite a healthy man" with just "a bit of hypertension", and recounts her embarrassment at having unwittingly revealed details of the amount of medication she has taken in her life:

- (16) Sue:           and are you aware of other people with high blood pressure...is this something you talk to other people about?
- Josephine:        I learned my lesson from my father-in-law  
                      who is in his eighties  
                      and who is now  
                      he's still quite a healthy man  
                      but he has got odd bits of angina  
                      and sort of a bit of hypertension  
                      and he's told me what he's taking  
                      and of course when he said to me "oh I'm on Atenolol"  
                      and "I'm on this and that"  
                      and I was saying "oh yeah I've taken those  
                      yeah I've taken those"  
                      not listening to how it sounded  
                      and then he he turned round  
                      and said "God she's got to do better than me  
                      she's always taken everything I've taken"  
                      and I thought "God help me from ever discussing anything like this with anybody ever  
                      again"  
                      <LAUGHS>  
                      because I really actually don't talk about it that much  
                      it seems to me it's not intrinsically interesting  
                      how many tablets you're taking..  
                      that stuff....  
                      so no the answer is no I don't  
                      and if I was ever inclined to I don't now

The only other narrative in Josephine's interview is a particularly significant one, for it relates a moment when her strategy for keeping the two parts of her life separate collapses. She rarely lets this happen, as extract (17) shows: here she mentions a single occasion when she allowed her 'ill self' to blend with her 'real self'.

- (17) Josephine: I did once tell a nurse in the renal unit to call me Josie and that was a huge leap of faith on my part but I really liked her and she really liked me and we got on really well and so she was allowed into my real life...it sounds bizarre doesn't it to talk about it like that but it's a way of keeping it where it should be I reckon

Before discussing the final narrative it is necessary to explain that Josephine developed close relationships during her stay in hospital with other patients undergoing a transplant operation:

- (18) Josephine: It's like being on board ship you know...you become your own complete little world and it's wonderful...you wouldn't get through it without...and there's lots of jokes and stuff you know it's a tight little community...highly supportive and you never forget...you never forget the day you had it done...you never forget the people you were in with who were having it done at the same time as you...it's a very emotional experience...whether it works or whether it doesn't it's a real high point

It is also relevant to note that when Josephine attends the outpatient clinic she does not wish to be reminded of her these experiences. She recounts in (19) how she identifies with like-minded patients at the clinic:

(19) Josephine: When I go to the transplant clinic for my routine visits it's actually a very friendly chatty place...hugely chatty...and there's always a few people who sort of bury their heads in a magazine and don't chat and ignore the overtures really because we don't need that club right now...when you need the club it's fantastic...it's a very supportive very efficient very effective unit and part of the support is that everybody is in there together...patients doctors nursing staff everybody...it's a fantastic place when you're ill...and when you're well you don't want the club because that would make you ill...if you responded you'd be ill you know...it's not everybody's view but when I look round the waiting room I can see the people who take the same view as me and they really don't want to know <LAUGHS> they don't want to catch anybody's eye to actually get into a chat with anybody...which you can easily do if you want to

We can now see that the narrative in (20) relates what must have been a traumatic occasion for Josephine, although she frames it as an amusing story by laughing at the beginning of her story. She remembers an occasion when she was in the outpatient transplant clinic at the same time as a woman who happened to be visually handicapped and who had received a transplant at the same time as Josephine. This patient was, therefore, one of the people to whom Josephine felt a great attachment, as described in (18). As a result she was forced to bring her two selves together – the "real me" who is well and whom she tries to preserve in the waiting room, and the ill self of the renal unit.

(20) Sue: and do you ever see those people you were in with?  
Josephine: <LAUGHS>

1. I was actually in the clinic about a year ago
2. and er one of my transplant mates was in there
3. was in clinic
4. and she is much more
5. she's quite a disabled person actually
6. she has a guide dog with her
7. and she has all kinds of ancillary problems as well as the kidney problem
8. and she was talking to someone
9. and she mentioned my name
10. and she said "oh I haven't seen Josie for ages
11. but I've seen so-and-so and so-and-so"
12. and I couldn't in all conscience sit two seats away
13. and I said "I'm here"
14. and chatted to her
15. but really broke my first rule
16. but er no when you don't need them you know
17. er it's a reminder
18. it's not what you want

Josephine does not tell many narratives, as we have said. We think it significant, therefore, that she chooses to dramatise in narrative form this traumatic encounter, where her strategy for coping with her illness broke down. It is also significant that there is a considerable amount of internal evaluation in this narrative, unlike the narrative in (13), in which she recounted her first experience of illness. For example, she describes the

other patient as her “mate” and gives details in lines 5-7 that make this patient’s disability more vivid: she has a guide dog with her, she has “all kinds” of ancillary problems, and she is “quite a disabled person actually”. The negative clause in line 12 is also a form of internal evaluation, contrasting what Josephine tells us she did with what she might have done. There are further negative clauses in the coda, in lines 16-18 (Labov (1972) explains how negation functions as internal evaluation in narratives of personal experience). The narrative contains direct speech; this, together with the details and images, and the focus on the participants and their feelings, creates involvement (Chafe 1982).

As we mentioned earlier, in the evaluation sections of their narratives speakers can establish the kind of self they present to their interlocutor (Linde 1993: 81); they can also make the point of their story clear. Here, then, the self that Josephine presents is a good, socially proper person (as she says in line 12, *I couldn't in all conscience sit two seats away*), and the reportability of the event lies in the fact that because she is a good, socially responsible person she was forced on that occasion to break her own rule. It is significant that her narrative presents her friend as having more health problems than Josephine. She breaks off her *she is much more* in line 4 to present details of these problems, and in this way succeeds in portraying herself as a person who is healthy compared to others. The coda to the narrative, in lines 16-18, repeats Josephine's strategy for dealing with her experiences of illness, making it clear that this occasion was a unique aberration. In this narrative, then, Josephine succeeds in displaying an identity as a relatively well person whilst repeating – and therefore reinforcing – her strategy for coping with her condition.

### *Reported speech*

Like Rose, Josephine reports some of her interactions with doctors and other health care professionals. Unlike Rose, however, there are only three clauses where Josephine reports her own speech with, by contrast, 31 clauses where she reports the speech of the professionals. Only one of Josephine's reported speech clauses is in the form of direct speech, compared to 28 (90 per cent) of her doctors' reported speech clauses. The imbalance constructs the doctors as more powerful participants in the interactions. The content of the doctors’ talk has the same effect: Josephine shows them telling her how to manage her illness and she presents herself as grateful to them for "sorting her out" and for enabling her to live a full life. Although she mentions several doctors approvingly, such as the GP who suggested she should stop smoking, there is no attempt to construct her interactions with them as anything other than the stereotypical doctor-patient interaction, where the doctor has the upper hand. This fits with her strategy of relegating all things concerning her illness to the part of herself who is not the "real me". Unlike Rose, whose narratives present the doctors as her friends, Josephine uses her narratives to keep them at a distance.

### *Summary: Josephine*

Josephine, as we have seen, copes with the experience of illness very differently from Rose, yet she appears to be equally well-adjusted to her medical condition. As in Rose's interview, this is revealed through the narratives Josephine tells, although in Josephine's case they display only rare glimpses of her personal identity. Perhaps if she were talking about something other than her experiences of illness she would be more likely to display her 'real self' in her stories. In the interview Josephine defines her identity in relation to people who are well – or, in her final narrative, in relation to a person who is far more disabled by her condition than Josephine – and she adopts a detached style when relating specific events concerning her condition. In this way she maintains and reinforces the attitude we saw earlier, in extract (3): “the real me is a kind of observer of this and so it doesn't get to me”. Unlike Rose, Josephine has constructed a personal identity as a well person, but nevertheless she can successfully integrate her two selves – the "ill person" and the "real me" – when it is necessary.

## **Conclusion**

Our analysis confirms, we believe, that narrative can be an important resource for people who have to adjust to living with a chronic condition, helping to reinforce the strategies they have developed in order to cope with the everyday demands of the condition. Although Rose and Josephine have reacted differently to the experience of living with illness, there are some similarities in the functions that their narratives fulfil in their interviews. First, narrative discourse allows them to interweave the objective and subjective aspects of knowing and understanding key events in the integration of illness into their life stories. Secondly, both women used narrative to locate themselves in their social worlds, drawing comparisons with others in ways that allowed them to simultaneously display their attitude to their condition and to create a self that was in harmony with what they perceived as relevant aspects of their personal identity. Their representations of interactions with health care professionals, in the narrative and non-narrative stretches of discourse, was in harmony with the place they wanted to give to these interactions in their lives. For both women, narrative provided a way for them to display and construct an identity as a patient and to integrate this identity into their sense of a stable, coherent, permanent self.

## **Note**

We have edited some of the non-narrative extracts to remove what we perceive as false starts, to make them easier to read. No editing of any kind has been carried out on the narrative extracts.

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