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## **NEGATIVE ATTRIBUTES OF SELF: RADICAL SURGERY AND THE INNER AND OUTER LEIFEWORLD**

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### **INTRODUCTION**

This chapter considers the impact on self and on public identity construction of radical abdominal surgery. The surgery is total colectomy and ileostomy which is performed to cure the disease ulcerative colitis. The mechanisms whereby self presentations are constrained in various ways by the after-effects of surgery, are explored. These constraints, it will be argued, are twofold. First, they derive from the immediate problems which are generated by wearing a surgical appliance and being faecally incontinent. These impact directly on the centre of the lifeworld of the person who has had the surgery (Schutz, 1964; 1967; 1970). In turn these problems may be significant in identity construction in social interaction. Second, the after-effects of surgery impact on self and identity via an inter-subjectively understood notion of the symbolic meaning of this particular procedure and its sequelae. The inter-subjectivity derives from a range of negative cultural categories which actors draw upon pre-morbidly and post-operatively. Pre-morbidly the negative categories are of marginal significance to the lifeworld of the person. Post-operatively they are central. It will be shown that those inter-subjective understandings may have profound effects on the actor, regardless of any physical constraints produced by the surgery, and to some extent independent of publicly constructed identities. In other words, the negative attributions are imposed internally rather than externally (cf. Scambler and Hopkins, 1986). It will be shown that the problems are particularly acute in intimate and potential sexual encounters.

This essay draws on earlier published material (Kelly, 1991; 1992a; 1992b; 1994a; 1994b; Kelly and Field, 1996). However, new data are presented and the theoretical arguments are developed with reference to a specific phenomenological perspective.

### **BACKGROUND**

Ulcerative colitis is an inflammatory disease of the lining layer of the gut. The inflammation results in symptoms of chronic unpredictable diarrhoea, loss of copious blood in the stool, pain, weight and appetite loss, and raised temperature. The causes of the disease are not known at present, and there is no medical cure for the condition. It is a disease of unpredictable course, sometimes occurring in acute form where the patient's life is threatened within a matter of days or weeks. In other cases, the sufferer may have a much more low grade experience of symptoms lasting for many years with periods of exacerbation and remission. The standard medical treatments when this research was originally conducted were the administration of oral or topical steroids and the use of an anti-inflammatory agent called Sulphasalazine (Salazopyrin). Steroids tend to be most effective in first onset and appear to be less efficacious thereafter. This leaves Sulphasalazine, which may itself have side effects such as nausea and male sterility, as the main palliative treatment.

When a patient is in an acute phase of the illness their life will revolve around going to the toilet. One of the great difficulties faced by a patient with colitis is the urgent need to evacuate. They not infrequently will have the sensation of requiring to open their bowels at once. In such circumstances they will have to stop what they are doing and go immediately to a toilet. As this urge is often quite uncontrollable, episodes of self-soiling are not uncommon. The sufferer may need to evacuate up to a dozen times a day and in very severe cases twenty or so or more times in 24 hours. The person with colitis therefore always has to know where the nearest toilet is, and simple tasks such as travelling, shopping, going away on holiday, going to social events become occasions fraught with danger and uncertainty. Of course, when the illness is at its most severe, the person will be too unwell to go out of the house anyway, and the sheer exhaustion which accompanies the loss of blood, the dehydration and the fever will lay them low. People whose symptoms are in remission will still have to attend to the potential unpredictability of their bowel motions. Even if they are apparently well, they may only get a few seconds warning of the start of a new attack.

There are some very serious complications of colitis. However, two are of especial note: toxic megacolon and cancer. Toxic megacolon is the disease process where the bowel literally expands until it bursts causing potential life threatening peritonitis. Colitis is a risk factor for bowel cancer. In persons who have had colitis for more than 10 years, there is a very greatly enhanced risk of the development of cancer, even where the symptoms have been low grade and apparently benign. This means that a person who is diagnosed as having colitis should be monitored regularly to ascertain whether any pre-

cancerous changes are occurring in the bowel. This involves two highly invasive procedures, barium enema and colonoscopy. In barium enema the barium is drained under gravity through the back passage into the colon. X-ray photographs are then taken. A colonoscope is a fibre optical instrument allowing the physician or surgeon to visualise the colon's surface and take out microscopic samples for investigation, again entering via the back passage. Both procedures are painful and highly undignified.

If pre-cancerous changes are observed, if the patient's life is threatened by some other complication, or their health and quality of life is extremely poor, then the only treatment option is radical surgery. This may involve the complete removal of the large bowel (colectomy) and the redirection of the small bowel through the abdominal wall (ileostomy). Following surgery, an appliance - a bag - must be worn by the patient who is made permanently faecally incontinent. When the research on which this chapter is based was done, this was the standard surgical procedure in use. More recently, other techniques have been perfected in which an internal reservoir or pouch is constructed. For some, these pouches still require external drainage with a catheter. Alternatively, the pouch is linked to the anus, so something approximating to normal defecation can occur. All these procedures are major. For elective as against emergency cases however they carry very few risks, but they do carry a considerable post-operative residue with which the 'cured' patient has to live for the rest of their life.

Colitis tends to be a disease of early adulthood. So not only do sufferers have to contend with a major illness they are also often in the throws of coping with all the problems and difficulties associated with taking on adult statuses and responsibilities, jobs, relationships and children.

## **METHODS**

The data for this paper were collected in a series of semi-structured interviews with people who had colitis and were waiting for surgery, or who had had surgery after a previous period of time with the disease. These interviews initially took the form of a guided conversation about the principal features of the natural history of the disease. However, after the first couple of interviews had been completed it became clear that with one simple question i.e. 'Could you tell me when you first noticed there was something wrong?', the respondents were able to talk at considerable length with a minimum of guidance. The objective was to get the people to talk as freely and as openly as possible.

Some 50 or so interviews were originally conducted. However, only 45 were analysed in depth, because some of the subjects when interviewed turned out not to have had colitis, or to have had some other kind of surgery. In a couple of cases the tape recorder failed to record, in two further cases relatives interfered with the interview and effectively took it over. All the interviews were tape recorded and then transcribed longhand. Then a simple thematic analysis was undertaken on the basis of the main features of the disease, what the literature on chronic illness suggested should be key ideas, and themes generated de novo from the transcripts themselves. These were cross referenced on a manual card index and sorted for purposes of generating categories and theoretical constructs. A great variety of themes emerged in the process but one of the most significant concerned ideas of self and identity. A limited amount of data relating to those concepts are presented in this chapter.

The sample itself was generated in several ways. In the area where the research was done, the names of people who might be prepared to be interviewed were obtained from several surgeons and from nurses engaged in stoma care. Also two branches of the Ileostomy Association were visited and volunteers recruited. At the beginning of each interview the volunteers were told what the purpose of the visit was - which was to obtain information about the experience of colitis and surgery from the patient's perspective.

## **THEORETICAL STARTING POINTS**

The conceptual structure of the chapter begins with a simple distinction (following Ball, 1972) between self and identity. In Ball's view, self is ego as known to ego i.e. that idea that each and every individual has in their mind's eye of who and what they are. Identity, in contrast, is ego as known to others, i.e. the way the individual is seen, perceived and defined by others. In this view, self is not some biologicistic or psychologistic 'thing'. It is rather the way that internally the individual objectifies themselves to themselves. Self is both experience in the here and now, and, a remembered past and an anticipated future having apparent existential continuity. The medium which links the self of experience to the self of past and future, is language and particularly the narrative stories and accounts that the individual uses to present their self to themselves, and to others. Through language self can objectify. That is it can think about itself in the same way that it can think about objects in the immediate, imagined or remembered environment. It can therefore imagine how it appears to others and can anticipate various identities that may emerge in interaction.

As interaction unfolds, self may become aware that the way it wants to be recognised and understood by others, is not happening. Everyone sometimes feels uncomfortable in the situation in which they find themselves and notices that they are misperceived by others. Some aspects of self and public identity on the other hand are rarely equivocal. Gender, approximate age, racial grouping are not generally ambiguous, although particular individuals may go to great lengths to deceive others in this regard. However, it is when the major axes of social differentiation are left behind and the focus is on social roles and behaviours which are not unambiguous, that the potential for misunderstanding arises. Guessing a stranger's correct occupation, or the type of school they went to, for example, is both a party game and the heart of a good deal of interaction between strangers. The rituals of interaction between people who do not know each other involve subtle processes of revealing identity markers, and covering up faux pas and misunderstandings. In certain settings key badges of office such as a doctor's white coat or stethoscope, or the fitter's tool bag help to establish relative identities. But in the absence of badges of office, interaction between strangers is about uncovering enough to establish identities and to allow interaction to proceed. Props of all kinds are routinely used in interaction, and costumes and well rehearsed starter scripts like 'Hello, how do you do?' 'Very well thank you' are all widely used to assist in these processes. Underlying obvious identity markers are a range of other facets. Selves and identities both attract and may try to attach themselves to particular moral, social and emotional characteristics. Self may lay claim to certain virtues, vices, beliefs, values, attitudes and so on, and identity may be linked to these moral characteristics too if such virtues or vices are publicly acknowledged.

So far the model presented here is based on the notion that interaction is problematic, people have to work to make interaction a success (i.e. it is a highly skilful activity) and that language and talk underlies the process. These are common enough ideas drawn as they are from observations of writers like Schutz (1964, 1967, 1970), Garfinkel (1967), Goffman (1969), Mead (1934), James (1892), Stone (1962), and Rosenberg (1981). What is of particular interest in this chapter is the impact on self and identity of illness and surgery, and the attempts to present self and the processes of legitimation which then come into play. When someone has an illness or a condition that actually or potentially cuts across interaction a new dynamic is established in that interaction. The extracts chosen to demonstrate this phenomena relate to an area of human conduct where feelings of self and socially constructed and negotiated identities are especially acute anyway. This relates to sexual or romantic encounters. Notwithstanding sex education, reams of advice and a good deal of media coverage and role modelling, arguably most potential new sexual encounters are intrinsically

problematic. Most people, at least at some point in their lives, find them embarrassing, difficult and awkward. This chapter considers what happens to self and identity following major surgery, which creates faecal incontinence, and the need to wear an appliance on the abdomen. It also examines the impact on interaction and for self of cultural stereotypes in these processes.

## THE DATA

Several extracts from the various interviews are now presented. The first series of extracts is from the interview with Georgina (a pseudonym). When Georgina had surgery she was 35. She had had colitis for about five years and her health had deteriorated to such a degree that an operation was recommended. She was a manual worker, unmarried and living on her own after the break-up of a long-standing relationship. Her mother and father lived nearby in the same town. Before the operation she expressed many fears about what her body would look like after surgery, and she also expressed a great deal of anxiety about the pain that would ensue after the operation. Although she was both by her own admission, and visibly, very poorly, she had been a very reluctant recruit to surgery and had had to be talked into it by the stoma nurse. Georgina discussed at length issues relating to appearance, and attractiveness. She is here describing what happened when the stoma therapist had been in to the hospital to change the appliance for her:

‘She changed the bag for me one day. But we had an awful carry on. Cos every time she just went to put a new one, a new bag on, it just started leaking again. Cos, I wasn't, the first stages where it was solidifying or anything. I thought "Oh my God", it was horrid. I thought it was really, really horrible y'know. But, I thought, "Have I got to look at that all the time?" ’

Georgina here is describing the not uncommon revulsion which many people with ileostomies feel when they first have their operation. The physical alteration to their body and the physical presence of the stoma seems to have done something profound to them in a way that is unwelcome and disagreeable. Many patients are discharged when they still have feelings of profound doubt and worry about their body, and a degree of uncertainty about their self. For many, and Georgina was a case in point, their whole sense of who and what they are has been undermined, or at least severely jolted by the experience of the surgery and the physical presence of the stoma and the appliance. What also happens is that while they are in hospital their overriding identity as far as their doctors, nurses and family and carers have been concerned, is as a patient and as someone undergoing major

surgery. In that sense, the patient's anxieties are reflected back to them in the institutional structures of the hospital environment. Once they leave hospital and they resume other roles again, the incongruities between self and identify really begin to emerge. Here Georgina describes an early outing when she still felt delicate and uncertain:

`.There was a bloke stopped me in the pub on Saturday night when I was out wi' me pals .... And he says "You're looking fine now", he says, "You're getting on". And I says, "How do you [inaudible]", and he says "You looked absolutely horrible", and I says, "Oh thanks very much, ha ha"! He says, "No, but you're looking fine now, and everybody's saying that" `.

While this little interchange could be put down to nothing more than good manners on the part of the `bloke' it nevertheless presented a dilemma for Georgina. She was flattered, and pleased, but also her apparently normal external appearance was at odds with the way she herself felt and she knew herself to look underneath her clothes. She felt disgusted and she thought others there would be disgusted also.

Georgina had continuing doubts about how she would cope:

`I'm not so bad now, but I found when I just came home, I sat. Came home, I spent half my day in the toilet. Every two minutes I was away thinking, "I'd better empty this, I'd better empty this". And same as when I go to the pub. I sit and I go, "Oh God, I think this is needing [emptying]". And rather than go in a public toilet, I go home and every thing. I don't have any confidence. And my pal says "You canna carry on like that, ya have to". And I say "I can't go to these toilets and stand, in the pub, with everybody drunk and I just thought "Oh no". But I'll just have to get used to it'.

Here we have a situation where Georgina's friends and acquaintances are attempting to construct an identity for her as a well or a recovered person, while she herself does not feel that she is either of those things. Furthermore, she does not believe that others really feel like that either. It is not the fundamental effects on self of the experience which define her self concept, nor the attempts by others to try to welcome her back from the sick role which defines her identity, but rather her own concern about the way she anticipates that others will respond which dominates her thinking. Ultimately Georgina remained very worried about embracing the `well' or `recovered' identity which her apparent `well' appearance demanded. She was

concerned because this would ultimately test her self - and her altered self might be revealed for what it truly was:

`I says to my pal, how could I be going out with somebody for a couple of weeks and then say "I've got something to tell you". I have a fear of somebody turning round and saying "Oh yeah" and going out the door and never coming back. Cos I think if someone done that, it would really hurt you. You'd feel depressed about it'.

One of the important transitions that occurs for someone who leaves hospital is the change from being someone whose whole identity is defined with reference to their acquisition of an ileostomy i.e. their time in hospital, to one where while their own sense of self is still defined with reference to the stoma, their public identity is defined without any reference to the stoma at all. The latter occurs where the individual finds themselves in social situations where others with whom they are interacting are quite oblivious to the surgery. Non-disease and non-surgical cues provide the basis for identity construction. In these circumstances, in the ordinary run of things, there is no need for the person with the ileostomy to say anything about their ileostomy to others at all. Their own concerns about their stoma are, and can remain, private. However, that is not the case where potential sexual or romantic encounters are concerned. Knowing how to, and feeling confident about handling this aspect of presentation of self can be a major source of anxiety. In certain circumstances the person with the ileostomy feels uncomfortable about passing themselves off as someone without an ileostomy. At the same time they have no easy way to manage the presentation of self involved. One young respondent eloquently expressed problems generated by this tension. She is Frances (again a pseudonym). She was 21 when interviewed. She was a clerical worker who at the time of the interview had had her stoma for four months and was still feeling acutely embarrassed by the whole thing. She had had a very sudden onset of colitis and had got to surgery in less than a year from when she believed the first symptoms had appeared:

Frances: `I can't really face telling anyone about it. People [by whom she meant professionals involved in her care] keep saying it's nothing to be ashamed of. But I just don't feel ready to tell anyone about it. So no one actually knows apart from my family. I don't want to tell anyone just now. I think that's probably a bad thing in a way as well, cos I'm kinda keeping it all in. But I just don't want to. I think its going to be quite hard going, going back to work as well'.

Researcher: `Why'?

Frances: `Just getting back and facing everyone, just getting back into a routine'.

The interview then began to explore some of those feelings, and the impact on self can be seen clearly:

Frances: `I would get upset if I thought about it often enough'.

Researcher: `What would upset you about it do you think'?

Frances: `Em, I just think you feel unattractive really with it. I think it just makes you feel like that. Just, unfeminine .... I was lucky. If I had been married, if I'd got married when I was supposed to get married, I think, I don't know, I think I'm glad I didn't, looking back. I'd rather be on my own'.

Researcher: `Really'?

Frances: `Mmmm'.

Researcher: `Why'?

Frances: `Not forever. I just mean just now. Just until I can come to terms with the thing myself. I think it would be hard to tell someone, I think it would take me a long time before .....'.

Researcher: `What do you mean? A prospective partner'?

Frances: `I'd have sort of feel. They would have to get to know me first, before I'd tell them. I wouldn't just go out with someone for a couple of dates and then tell them'.

Frances is grappling with several things. First, she has a view that her particular condition will be stigmatised by prospective partners. She does not believe this on the basis of any evidence that the ileostomy will be the defining aspect of her identity. She had no direct experience of this happening. At the time of the interview she had told no-one outside of her family circle. Her anticipation was not on the basis of bitter experience. Her anticipation was however on the basis of cultural values and norms which she was drawing upon where her own sense of recoil from the stoma was objectified onto others. In a Meadian sense she is role taking and imagining the way others might perceive her (Mead, 1934). By drawing inter-subjectively upon various cultural norms relating explicitly to femininity, and

implicitly to attractiveness, she finds herself wanting and believes others will do so too. Second, she is objectifying her own self. There is the self which is impacted on by the stoma, and there is the 'true' self - the real her which is more important than the self defined with reference to the stoma. She has concluded that she must have time with a prospective partner so he can get to know her. By this she has some idea of a life in which the stoma is unimportant. Frances wants the opportunity to construct an identity which is not one based on her stoma. What she had yet to do, at the time of interview, was to find a way to deal with this herself and carry off the presentation of self in which 'I am more important than the stoma' was the dominant motif.

That Frances should feel like this is hardly surprising. Another subject offers a graphic account of why this is so. She is Lana, a nurse. She was 20 when interviewed having first been diagnosed as having colitis when she was 18. Here she is describing her experiences in hospital after she had had her operation and at the point when she was mobile enough to be taken to have a bath:

'I remember the first time I had a bath. And they decided they were gonna change it [the appliance], y'know. And the bags that y'get in hospital, y'know they've got the brown stuff all around, and it all sticks to you, and every thing. And it wouldn't come off. And it was all over the bathwater and oh! And I started crying in the bathroom y'know, because it was all over the place, and, I just think, I thought that when they [the nurses] looked at me, they must be disgusted. Because they see this, and it was horrible, y'know'.

What is so interesting about this quotation is that as Lana does the role taking she is not simply imagining in a vacuum what the nurses might feel. She is a nurse herself and she had nursed stoma patients. She knew how she felt about that, and therefore she thought she had a pretty shrewd idea as to how the people nursing her would feel. She had access to 'privileged' back-stage talk, which she knew was negative. The problem of access to what is otherwise privileged discourse, caused further problems for Lana. She dearly wanted to keep public knowledge of her condition to a minimum. However, she lived in a small village some 15 miles from the main town, where the hospital was where she had had her operation. She found the local gossip (which is of course a form of public identity construction) hard to cope with:

Lana: 'I mean people have said to me, back in Budling, mm, all I say, I'm not lying, but I'm not telling the truth. I just say I had to get a bit of my bowel taken out, and they don't know ..... They don't know that it's

a whole total colon, or with Crohn's disease you can get a resection, I mean they don't have a clue, so they don't know'.

Researcher: 'Is it important to you not to tell them'?

Lana: 'Just now'.

Researcher: 'Why do you think that is'?

Lana: 'Er, don't know. Budling's such a small place and they all look at you, y'know. And the girl said to my sister, well a woman actually, who'd found out. And she said to my sister "Oh God, what a shame. That's terrible, y'know, that poor girl, She's such a bonnie lassie and she's had to get that horrible operation?" And I thought, "Oh God, if this is what I've to face when I come home I'm not telling anyone". Y'know, cos my sister told me, but, I had, I've had a really bad time since I came home, because I got out on 18th February, that was Thursday night. Friday night we were having fish. So I went out to the fish shop [she met someone who asked her how she was feeling] And I say "Oh fine". Being such a small town I thought, "Oh she's heard I've been in hospital", y'know. And eh, and I thought that was as far as the conversation was going to go. And she said, er, "That was a terrible operation that y've had". Y'know she's standing looking at my tummy, y'know, she says "How do you cope with that bag thing"? y'know. I sort of looked at her because I hadn't told anybody outside my family, and I know that nobody would tell her, and I thought "How the hell do you know"? And I didn't look annoyed and I just said, "Do you mind telling me how you found out"? "Oh my sister's a staff nurse in theatre" '.

This breach of professional etiquette caused Lana enormous distress, because her inability to define not just her identity, but her own sense of self as reflected back to her was removed. Selves and identities are not static things. They are in a relationship of constant flux with each other. Self is presented, identity is negotiated and self is redefined and represented in a never ending process. What is crucial here is that as self is presented, it is not or only partially legitimated, and instead a very particular definition of identity is applied which Lana had not wanted but she was now powerless to do much about. Small wonder that later in the interview she made this comment.

Lana: 'Every night when I go to my bed, and that's where I do most of my thinking. And you lie and think about it. And it's, it's the thought

"God I've got this for the rest of my life", y'know, em, people keep saying "It'll become part of your life", but I don't know yet'.

These concerns are not simply psychological worries and fears but they relate to the fact that the sense of self is tied into the technical efficiency of the appliance. This helps explain why and how the ileostomy can become such a dominant concern. In order to feel confident and to engage in presentation of self in a way that appears to be unexceptional and ordinary requires that the ileostomy be bracketed out of feelings about self and therefore bracketed out of interaction more generally. If an appliance leaks or falls off, the game is up. It will make a mess. It will smell and a replacement will have to be found. The wearer's fear is that this might happen at any moment. Steven explains:

` Y'see I'm a very active person, and I thought y'know "Is this gonna come apart"? No, I thought if I'm really active and hill walking and things like that, "How am I gonna hill walk for a full day"? Y'know, walk 20, 25 miles. How am I gonna be in that time? So the stoma therapist provided me with ... the belt ... so that gives you confidence, because that is what I was needing. I had confidence till I had a few failures [leaks]. I had a few failures, and the confidence soon goes. It goes very quickly'.

Researcher: `You had some accidents [leaks] did you'?

Stephen: `Well one, one came adrift and er that ..... it was in the house, but I thought if I was in the middle of a hill, or the middle of a shoot and that happened, I'm in deep trouble. So that's when I lost confidence and got very depressed about it. That's when, I say, I suddenly realised. Oh, I knew it was for life certainly but eh, but it really got home to me at that point'.

What Steven is struggling with here is that he wanted other things in his life to be more important than his stoma. The country life of walking and shooting, was an expression of the self he wanted to be. He was however concerned that the unreliability of the stoma would override his efforts. In this sense he is quite right since the presentation of self and the recognition of this by others, is for the person with an ileostomy critically dependent on the ileostomy, being under the control of the person who has it. This can never be an entirely taken-for-granted aspect of life for the person in this position. The forceful salience of the ileostomy will vary, but it can never be entirely ignored or forgotten about.

Nevertheless it does seem to be the physical scarring and the stoma itself which seem to exert the most profound influence on self, and not just in people who are anticipating relationships, but to people in long-lasting ones. Tricia, a clerical worker, for example, was 49 and had been married for more than 25 years. She was less than a year away from surgery when interviewed. She explained her anxieties:

`It was just that I em, when I looked at my body, and saw the big scar, and this [the appliance] at the side, I thought "Oh Heavens will Gregor [her husband] ever look at me again". Which is really ridiculous. Y'know. He is a very loving person'.

She explained how this concern had caused her to cry. Tricia was someone whose marriage was very secure, and where husband and wife had in fact been through many shared difficulties over the years. And yet she still felt that her identity as defined by her husband might be fundamentally transformed. The power of the negative feelings about self to be extended to others, is considerable. And this happened in spite of the fact that she herself felt quite positive about how she managed her stoma:

`I'm amazed how I've adapted to it. And er, honestly I forget that I've got it at times, and I've, and it's not until I feel the bag getting heavy or swollen, y'know, if there's any wind in it, that I realise that there's something there. It, y'know, I've been amazed at how, I have adapted to it and I've found myself in the kitchen the other day, y'know when y'r working away with both hands, you sort of shut the drawer with the hip bone and realising "oh! better not do that", y'know having completely forgotten that it was there'.

This quotation helps to illustrate another facet of self. For some people with ileostomies, as time goes by, the salience of the stoma and the appliance fade and other more mundane aspects of life and subjectivity assume importance, or reassume importance. There is a clear imperative that life goes on and the post-operative patient has in some way to integrate with or to obey the imperative. In hospital their entire sense of self and their whole public identity was rooted in the presence of the stoma and in the experience of surgery. Profound as these experiences are, there is status passage onward. However, as these extracts also suggest while self may grow more comfortable with the surgical residue, self also is acutely aware of the possibly negative aspects attaching to when the stoma is public - even with the most intimate of associates.

Barbara, a young respondent (22 when interviewed) and at that time unemployed and unmarried, shows some of the acute concern that negative identity construction will occur.

`One thing I can remember, eh, the day that they told me, that I was going to get out of the hospital. When they said right, you're O.K., you're gonna get out the next day, er, I didn't want to go home, because I was sorta secure in the hospital. Well I did want to go home, but I didn't at the same time, and er, the day that I got out I just felt like bursting into tears. I didn't like, I'm the kind of person that hides my emotions, but I really felt like bursting into tears because I'd left the security of the hospital, and I didn't know how other people were gonna react'.

Barbara took a very direct approach in the end and used this directness to try and influence the way identity construction occurred in relationships, with varying results. She describes two of her relationships:

`Well you don't have to tell them because, I mean, I don't know, people, I suppose I well you don't have to tell them unless you're in any situation where you feel you must, I s'pose. My last boyfriend, I told him, er. I sorta put it off because, eh, I had this boy before right, and er, I'd just been out wi' him a couple of times right, and I sorta. He sensed that there was something wrong with me. I just sorta, I don't know, I just sorta clamped up, em, and I just sorta, I thought to myself, right, I'm gonna tell him because, because, it just wasna doing any good, right. So I told him, and he says "God, what does that matter"? He says er, "I mean", he says, "To tell you the truth, my grandad's gone through the same operation". And I thought it was really genuine and everything. The next time he saw me, he never spoke to me or anything, and that sorta put me off, y'know telling anybody, cos he seemed really genuine about it. Ah, "Oh God, that's nothing, I mean my grandad's had that operation, and I mean I know what its like, and why should you bother about what people think"? And all the rest of it. And the next time he saw me he never even spoke to me. And I thought. And I thought "God", and it really knocked me back. So then, er, my last boyfriend em, I'd been going out with him a couple of months and er, I searched, I kept putting off. I wanted to tell him. But I just sorta kept putting it off. I thought, should I tell him straight away, so I will know whether it will bother him or not. So he can just sorta go away and that will be it. And if it doesn't bother him, sorta keep going out with him. So I knew straight away whether he was bothered or not, and I just sorta put it off and put it off, and then one night I just told him. And I

mean, he just sorta sat back and thought, "God, what's this"? He says, "I'm really shocked"... Cos I'd been going out with him for about three months. I mean he never had any notion, never thought anything about it, never noticed or anything. And he just accepted it. He just didn't bother at all. He says, "It doesn't bother me", he says, "God, I've been going with you for three months", he says, "I really like you", he says, "You don't think something like that's gonna bother me". I'm no going out with him by the way. But that was, I mean we fell out about something else'!

This final extract demonstrates some of the ambiguities and difficulties involved. Sooner or later if the relationship is to progress, the person with the ileostomy has to present this aspect of their self to others. That aspect of self may be something they are very comfortable with, or it may be something from which they metaphorically recoil. Either way, when they reveal this aspect of their self to another, or as in the case of Tricia, they want to resume a normal life with a spouse, there is a potential danger that it will not be some of the positive facets of self which will be acknowledged and legitimated by the other person. It might be precisely that aspect of self which is so negatively evaluated by self, which could from the core of the identity imposed, negotiated or developed, by the others.

This happens in non-sexual relationships too and the issues being described here apply more broadly. A version of self is proffered in speech, deportment and dress, and a response is made in which identity is confirmed or developed. Interaction is by definition a processual thing and in that sense all interaction is potentially unstable. For the person with an ileostomy, the ileostomy itself provides for an added dimension of potential instability.

## **DISCUSSION**

In the previous sections a model of the relationship between self and identity has been sketched out and some data have been presented to illustrate the proposed model. In schematic terms this may be restated as follows: self is a multifaceted phenomena borne on the data of internalised talk and presented to others via speech, dress and deportment. Self is not a thing, and exists only in the present here and now. However, through language it does have a sense of itself in the past and in an anticipated future. Before, during and after interaction self anticipates the response of others to its presentation and draws upon a stock of cultural knowledge, beliefs or experience to do the anticipations. During interaction, identity emerges as a consequence of the presentation of self and the responses of others (which are themselves

similar processes of self-presentation). In the case of the operations described here, the surgery has a profound influence on, and is a highly salient facet of self. Although it may cease to be prominent in the internal lifeworld, it remains a significant feature of anticipated and actual interaction, especially where degrees of intimacy are involved. That significance is drawn from inter-subjectively shared understandings of the world. Self and identity are forever in a process of becoming and are not ever in any sense complete. They are constructed and reconstructed constantly in interaction, in memory and in talk. However, despite the malleability and mutability and the process of becoming, certain key markers provide points of anchor for self and identity. The obvious ones associated with age, gender and ethnicity provide aspects of self and identity which for most people carry over time and place. Social roles, occupations and statuses, while less dominant in an analytic sense, nevertheless provide for key constants in many people's lives. Chronic illness or body altering surgery are other constants, and their implications for social interaction are potentially profound. However, the term 'potentially' is used here quite deliberately to try to capture some of the tenuousness of the processes involved.

Old fashioned role theory not infrequently tended to assume a fit between people and the roles they played (Dahrendorf, 1968). Early sociological theory held that becoming a human involved learning particular social roles and playing out the appropriate performance. While it was recognised that people might interpret roles somewhat differently, the notion of a fit between person and role was assumed. There is a sense in which having a chronic illness or having particular types of surgery or for that matter other forms of impairment, could be conceptualised in this rather old fashioned sense. Sadly however this kind of thinking leads to some unhelpful stereotypical accounts of illness or 'disability'. The person is the role. In these cases the person becomes an ileostomist or an ulcerative colitic. What happens is that the person becomes the role and the role becomes a social category loaded with meaning. Sociologists and writers involved with the disability movement have rightly criticised the naivety of the original theoretical position and the ideological nature of the social categories thus generated. However, just because they are theoretically naive and politically incorrect does not render such categories unimportant.

Certain categories such as chronic sick, colitic, ileostomist and others are part of the cultural capital of society. As with all stereotypes, these categories are drawn upon by cultural actors and serve not just ideological purposes, but also act as a functional shorthand. For most social actors those categories exist in what Schutz called the outer zones of relevance of the lifeworld (Schutz, 1964, 1967, 1970). For persons who do not have to confront

the reality of disease or surgery in the here and now, the categories function as a reference point out of their immediate range of interest. In this they co-exist with many hundreds of similar categories of more or less relevance.

Once illness and surgery enter the immediate lifeworld of the person and their family, the issue the person has to deal with is coping with the practical problems generated by the illness. Most assuredly there is not a one to one fit between the person and the illness, because as these data show the nature of the illness and the surgery has varying degrees of salience depending on place, time and context. At the level of self, the individual will not only have to confront the daily graft of managing the illness and the post-operative sequelae, but also have to manage all the other aspects of their lifeworld too. However, and this is where the processes conjoin, the erstwhile categories from the outer zones of relevance do not vanish and are not expunged. They remain a significant resource. At the level of self, the individual will be cognisant with the fact that they are much more than their ileostomy or their colitis, and they are a 'real' person not just a stoma. However, in the anticipations that they make of other people's responses to them, they draw not only on their own experiences of illness and surgery, but also on the cultural categories derived from their understandings of those things before they were ill. They anticipate that others, who do not have their inner knowledge, will respond according to broad cultural stereotypes. In part, their task is breaking through the stereotype, of rendering it irrelevant, so that they can reveal their true self and develop a social identity in which other more important aspects of themselves are given precedence over the illness or surgery. In the case of the disease and surgery described here, that is more than possible in many interactive settings. When they are fully clothed their ileostomy is not visible, and for many people with colitis, for a good deal of the time they will not look desperately ill. The problem reaches acute dimensions in intimate or potentially intimate relationships when being undressed will render the appliance visible, or when diarrhoea might start at any moment. This is overlaid by another set of cultural categories about body shape, size and appearance which are highly loaded with meaning in the context of sexual attraction. The cultural stereotypes of sickness and stoma surgery would seem to be diametrically opposed to visions of loveliness and sexual desirability.

What this essay has tried to capture is two notions. The first is that while cultural stereotypes may be offensive, unhelpful and damaging, they are very real. They form part of a backdrop of cultural meanings which for most able bodied people are in the outer zones of relevance of the lifeworld. They are drawn upon heavily, however, by persons with the condition, not necessarily in their self concepts - although these stereotypes may form a clear part of

some facets of self - but will particularly form a strong component of anticipated responses from others in the negotiation of identity in presentation of self.

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