



# Liminality: A major category of the experience of cancer illness

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**Abstract** Narrative analysis is well established as a means of examining the subjective experience of those who suffer chronic illness and cancer. In a study of perceptions of the outcomes of treatment of cancer of the colon, we have been struck by the consistency with which patients record three particular observations of their subjective experience: (1) the immediate impact of the cancer diagnosis and a persisting identification as a cancer patient, regardless of the time since treatment and of the presence or absence of persistent or recurrent disease; (2) a state of variable alienation from social familiars, expressed as an inability to communicate the nature of the experience of the illness, its diagnosis and treatment; and (3) a persistent sense of boundedness, an awareness of limits to space, empowerment and available time. These subjectivities were experienced in varying degree by all patients in our study. Individual responses to these experiences were complex and variable. The experiences are best understood under the rubric of a category we call “liminality”. We believe that all cancer patients enter and experience liminality as a *process* which begins with the first manifestations of

their malignancy. An initial acute phase of liminality is marked by disorientation, a sense of loss and of loss of control, and a sense of uncertainty. An adaptive, enduring phase of suspended liminality supervenes, in which each patient constructs and reconstructs meaning for their experience by means of narrative. This phase persists, probably for the rest of the cancer patient’s life. The experience of liminality is firmly grounded in the changing and experiencing body that houses both the disease and the self. Insights into the nature of the experience can be gained from the Existentialist philosophers and from the history of attitudes to death. Understanding liminality helps us to understand what it is that patients with cancer (and other serious illnesses) seek from the system to which they turn for help. Its explication should therefore be important for those who provide health care, those who educate health care workers and those concerned to study and use outcomes as administrative and policy making instruments.

**Keywords** liminality · cancer · illness trajectory · narrative

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## INTRODUCTION

Measures of health outcome and quality of life, as reviewed by workers like Macbeth (1996), currently do little to capture the main preoccupations of those suffering from serious chronic illness (Robinson, 1990; Broyard, 1992; Toombs, 1992). We need better ways to make the subjective experience of illness more

intelligible to stakeholders in the health endeavour such as bureaucrats, administrators, politicians, economists and epidemiologists, who exert an important influence on clinical transactions, but who do so at arms length.

Within qualitative medical research there has recently been a surge of interest in narrative accounts of illness and in methods of narrative and thematic analysis (Robinson, 1990; Kleinman, 1988; Brown et al., 1989; Cassell, 1991; Good et al., 1994; Mattingly, 1994; Frank, 1995; Mishler, 1995; Cassell, 1997; Hyden, 1997; Steffen, 1997). These techniques have definite strengths. Narratives can provide an understanding of the experience of illness through the rich descriptions they impart, and the wealth of detail that emerges. Further, they provide an insight into the continuing process that is the illness trajectory. New methods of qualitative analysis provide the systematic means to explore and map this richness so that the important similarities shared by such narratives do not remain obscured by the individual variability that they emphasise.

While this “narrative turn” is useful for the purpose of exploring and communicating the subjective experience of illness, we are concerned that it is not sufficiently anchored in the central fact of embodiment (Csordas, 1994). Frank (1995) has emphasised the necessity to understand that the illness narrative expresses bodily experience. This is crucial in the contexts of medical research, education and practice. Other authors seem less concerned with embodiment. Cassell, for example, acknowledges the insights that we gain from examining patient narratives, but accords little space to the body in his examination of the nature of suffering (Cassell, 1991). Because of its reductionist tendency, conventional medical understanding also typically fails to capture the embodied experience of illness. By construing body and illness only in terms of organs, cells and systems, it tends to arrive at an understanding of disease processes, without necessarily achieving an understanding of illness as the experience of an embodied, suffering subject.

Our purpose is to find a way to capture the subjective experience of illness using narrative (because it is such good raw material) but in a way which grounds our understanding of illness in the central fact of its embodiment. In this paper we formulate and explore a category we call *liminality* which we think is useful for this purpose.

## MATERIALS AND METHODS

At weekly meetings held over six months, the research group used medical experience, published narratives of illness, film, television drama and interviews, radio interviews and informal discussions with patients and former patients in order to identify possible indicators of the nature of the illness experience of cancer patients. An empirical study was then designed and carried out to test concepts and categories developed during these discussions.

Two surgeons and a stoma therapist working in a large colorectal service in a Sydney teaching hospital were asked for a list of patients who had undergone colectomy for colorectal cancer, whom they considered able to talk freely about their experience and willing to participate in the study. Ten patients were then sampled from these lists so as to achieve a reasonable balance and representation by age, sex, presence or absence of a permanent stoma and length of time since colectomy. An introductory letter and information sheet about the study were sent to each selected patient, and followed up by a telephone call from one of the interviewers (KP or CJ). All ten selected patients agreed to participate in the study.

Interviews were conducted, according to the patient’s preference, either at the patient’s home or in a comfortable private office at the hospital. After signing a consent form, patients were invited to tell the story of their illness, starting from the first intimations of their illness. The narratives were elicited with minimal prompting. The interviews were taped, transcribed and edited for accuracy and emphasis by the interviewer. The transcripts were analysed using grounded theory (Strauss and Corbin, 1990; Denzin and Lincoln, 1994), reflexively modifying hypotheses in the light of progressive observations. Transcripts were coded for significant themes by KP, CJ and ML. Coding consistency was achieved by weekly meetings at which codings were discussed, compared and agreed. Ethical approval for the study was obtained both from the participating hospital and the University of Sydney.

## RESULTS

Transcripts of completed interviews were obtained from five men and five women whose median age was 60 yr, with a range of 39–79 yr. Interviews lasted from 50 to

90 minutes. Five patients had permanent stomas, and three of the remainder had had temporary stomas which had been closed. The median time since colectomy was 38 months, with a range of three to 144 months. One patient was receiving adjuvant chemotherapy, and one had received adjuvant radiotherapy preoperatively. Five patients experienced major complications requiring additional treatment after surgery. One patient had proven recurrent cancer, and a second was undergoing investigation for suspected recurrence.

In all of the narratives, patients expressed the subjective experience of symptoms, diagnosis, treatment and follow up through three main themes:

1. the theme of *cancer patientness*, which encompasses the immediate impact of the cancer diagnosis, and persistent identification as a cancer patient regardless of the time since treatment, and of the presence or absence of recurrent or persistent disease;
2. the theme of *communicative alienation*, which expresses a state of variable alienation from social familiars brought about by an inability to communicate and share the nature of the experience of illness, its diagnosis and treatment;
3. the theme of *boundedness*, which encompasses the particular ways in which the world “contracts” for the patient, through an awareness of limits to space, available time and empowerment.

These themes were expressed differently in ways which broadly depended on their proximity to the illness episode.

#### Cancer patientness

*Early in the illness episode.* Each patient spoke of cancer diagnosis as a confrontation with mortality. In the words of one patient, “You think of cancer? *Death*. I mean you just think of dying; you don’t think of the people that recover”. Responses to this perceived threat included confusion, disbelief and bewilderment. A number of patients immediately recognised that special strengths were now expected of them and began at once to gather and harvest their personal resources. Some expressed relief at the end of diagnostic uncertainty, while others acknowledged that a firm diagnosis introduced a new set of uncertainties about the effects and results of treatment.

A diagnosis of cancer also precipitated a sense of urgency both in the patient and in all those around him. “I had to drop everything”, said a businessman who bargained unsuccessfully with his surgeon for another week to clear his desk. Accounts of this period are characterised by a language of compulsion as patients yield to a seemingly overwhelming imperative. “This time I want you to go to Sydney”, a doctor is reported to have said, “You are going to have your whole bowel removed”. Patients resign themselves to the system and surrender control, recognising that the label “cancer” demands these surrenders, and that it accords the system special duties and powers. Some patients were relieved to hand over control; others resisted. One man coped with the need to surrender by embracing it: “My overriding remembrance” he recalled, “is that I was very pleased. I said ‘Get me to the hospital as quick as we can, and do it as fast as possible’”. Others signalled that this phase ends with the reassertion of control, first in symbolic ways such as tidying the hospital ward, or through acts of non-compliance such as leaving hospital early, or through attempting to control businesses or homes from the hospital bed.

*Late in the illness episode.* All patients spoke within their identity as cancer patients, regardless of the time since treatment. This persisting identification was expressed in various ways. Some dwelt on how everyday life had changed irreversibly. For one 74-yr old man, a permanent colostomy served as a constant and unwelcome reminder of his status as a cancer patient some eight years after surgery. “There is just nothing on the horizon, there is nowhere I can turn for the future”, he said. “I just live for the day”.

Four years after treatment, a 40-yr old woman with no stoma commented that “there wouldn’t be a day that goes by when I don’t think about it”. She described in detail how the iterative process of cancer follow-up reinforced the persisting sense of cancer-patientness. Reflecting on her falling carcinoembryonic antigen levels, she commented that “If it came back, I wouldn’t cope as well as I did the first time, because I think it would come back as a secondary which would be worse”. She also related how “I couldn’t plan any more than to the next check-up”. As the frequency of her check-ups decreased, there was a corresponding increase in the time horizon within which she allowed herself to plan.

Another 71-yr old woman, 12 months after surgery, said “Of course I think if I get a pain now, where is [the

cancer ]? Is it there? Or is it there? ... that's the only thing that is worrying me now". In the case of a 39-yr old man, follow-up tests revealed a possible recurrence of disease, and his worst fears had to be confronted. Reflecting on the fact that his family were saying he had cancer again, he protested "*I haven't got cancer, yet. We don't know what it is ... they have found something ... So virtually it is a waiting game, to find out what's the outcome of this one*".

Not everyone is overwhelmed or threatened by the sense of being a cancer patient. A 79-yr old man with a stoma, 12 years after his surgery, accepted that he was in some ways set apart by the experience of cancer, but insisted that "Life goes on". He worked as a volunteer counsellor for the hospital which treated him, providing advice and support for others facing the prospect of similar surgery. "I just sort of went back to hospital to help other people", he said. Others go out of their way to deny any sense of cancer patientness, but in doing so acknowledge that consciousness of cancer status is the norm among their fellow patients.

#### *Communicative alienation*

*Early in the illness episode.* People recognised that others could never really share the horror of the experience they had endured in the early stages. One couple in their late thirties produced a nightmarish series of images in their attempt to communicate the way they felt about arriving at the hospital ward. The wife said "And there's nurses coming at you left, right and centre, and they're using all these big words, and you are lost, you are absolutely lost. And then they bring this folder out, of [colostomy ] bags, and it's like 'Pick a party dress! Now pick a bag, what bag would you like?' ... We sat down on the bed and we both looked at each other and said 'Let's go! We'll come back later and get this done'. Because there was... a dead man sitting up in a chair".

Patients also recognised that there was no way to communicate what the experience of surgery and its aftermath would "really be like". A 57-yr old woman said " ... they have to talk to you about what to expect, and ... I don't think anybody can really tell you what to expect". A 74-yr old accountant recounted in detail the information he had been given before the operation, but commented that, despite the briefing, "I wasn't prepared for (a) the trauma that I would have to go through, and (b) the restrictions it placed on my life afterwards". Better communication seemed to be established if the

informant had undergone the same experience, and one of our patients had become a colostomy counsellor because he recognised this truth. The wife of one patient said "They should introduce you to people that have them [colostomies or ileostomies] and let them speak to you. Maybe you would find it a little bit easier to handle". The husband concurred, saying how strongly he had been impressed when a clinical psychologist reassured him that life with an ileostomy could be managed, a reassurance she offered with authority because she had an ileostomy herself.

*Late in the illness episode.* The separateness involved in being a cancer patient was closely linked to a sense of alienation which many people expressed as a distancing or loss of social familiars. This distancing was experienced partly as alienation, partly as a change in needs. One 39-yr old man said "Well, we have lost all our friends". His wife interjected " ... probably because they don't know what to say, and it's easier to stay away". A 71-yr old woman commented "I felt like I needed people but *different*, you know what I mean?" A further insight into the nature of this alienation came from an interview with a 63-yr old woman, with a stoma three years after surgery, who commented that her life had not changed much because " ... it wasn't much of a lifestyle anyway [laughter], so I'm not the one for that to be a worry ... Another person that was very social ... well they might have problems". Those with most to lose will feel the impact of social isolation most keenly.

Others express their sense of isolation by reference to the social expectations placed upon them, as did a 54-yr old Asian nurse, who recognised that she was expected to be "stronger than the rest of the family". At a time when she might have expected the family to support her, the family's distress made it impossible for her to express her distress. Others, like the 79-yr old man mentioned earlier, counter the isolation by supererogatory moves, offering to act as counsellors or advocates for others in the same situation.

Many struggle with the fact that the nature of their experience is impossible to communicate in words to those who have not undergone something similar. A 57-yr old woman with a stoma two and a half years after surgery, had this to say: "I don't believe I've had anything worse than most people, but I do know what it's about. I have experienced some things that people, some people, will never have". About her husband specifically, she says " ... I feel, sometimes *I just wished he would understand*".

Sometimes language “collapses” in the face of the recollection of the incommunicable. For example, one woman recalled the experience of losing her autonomy to the medical system: “But when I went in to the, to have my surgery, it was different, it wasn’t like I was embarrassed or I wasn’t, I had lost, because I had not really had anything before, I was a very private person, I was very um, I wouldn’t expose myself, you know, I was very ...” Crying was also a common extra-linguistic expression of profound emotion beyond the bounds of language.

### *Boundedness*

*Early in the illness episode.* Patients expressed their sense of boundedness in time and space, but also in terms of surrender of social and working roles, and as loss of empowerment. Images of confinement in space often expressed the sense of lost power and social role. They were “taken over” by the system, yielding control of their lives, their time and use of space. They were confined to diagnostic areas and hospitals, and met schedules dictated by others. In the early phase, boundedness expressed what was regarded as a necessary compliance with the medical system. One man, for example, said “I’m a self-employed public accountant ... I have lots of work all the time ... I had to drop everything”. The same man commented that there were “four beds in a little section”, and this section contained his world during the post-operative course. Another woman commented “The wards are *just something else* ... You’re all lined up like little soldiers in these rooms ... And very, very noisy”.

Patients depended very much on others for pain relief and for basic functions like washing. Bowel activity became a major preoccupation for most, whether they had stomas or not. These dependencies and preoccupations increased the sense of boundedness. One woman developed severe diarrhoea after a restorative resection, and said “...you would be on the toilet fifty times [a day] ...”

Going home was a major milestone because it promised some return to normality, with autonomy and self-determination. Most people quickly sought familiar things to do, and, in the words of one 40-yr old woman, a return to “the little things you take for granted ... just Being at home, being with my kids and washing up, washing the floor ...”.

*Late in the illness episode.* Most patients expressed perceptions of existential constraint, an awareness of the uncertainty of future time, of constraints on choice and empowerment, of limitations in the freedom to use space. Awareness of mortality and uncertainty about the future were prominent. One woman, four years after treatment and with no stoma, said “My outlook on life is different ... I worry about if I am going to live tomorrow”. A 63-yr old woman, with a stoma three years after surgery, said “I don’t think of myself as having a long life ... They said if it is going to attack another part of the body you usually find out in two years”. A 67-yr old man, three years after surgery and with no stoma, expressed the familiarity of death. Having detailed the history of cancer in his family, he said “I expected to get something sooner”. When his diagnosis of cancer was made he responded by saying “Whether it’s fatalistic or realistic, I don’t know...It is no good crying about things you can’t help, right? You go ahead and do something about it”.

Constraints on space were variously expressed. One elderly woman without a stoma, who had once enjoyed bushwalking and travelling, went on circular trips around Sydney. She said “ ... I can’t sit here brooding with myself. I’ll go and get on a train, go into town, or take a book and do the circle around and read my book on the way round from the city ... ”. These circular trips on familiar routes were in part determined by the availability of lavatories and wash rooms: “I had to make sure where I was going and whether there were toilets ... ” Bathrooms loom large for those with stomas. A 57-yr old woman with an ileostomy said “ ... when you have an ileostomy, it has to be emptied, say, eight times a day... You go there, figure out how you are going to start, which is the best way to do it, and kneel down at the toilet, with your *head in the toilet* more or less while you are doing it, and you think it is really revolting sometimes, you sort of think this is the pits, your head in the toilet half the day”.

Limitations of choice and power are particularly important for those whose social role is to a significant extent defined by their work. A 39-yr old man with a stoma commented that “That’s just living with something. Look, your whole life changes from virtually being an active person down to a nobody”. A nurse, four months into her chemotherapy, stressed that “ ... I haven’t gone back to work yet, no ... I have worked for so many years ... I never had such a long spell not working”.



Once again, this sense of boundedness can be countered by supererogatory action. Even those who had not volunteered to act as counsellors and advisers commonly expressed their wish to do something positive within the constraints of the cancer patient status. For example, one successful and assertive business man said “I just at times thought I should go and talk to people about this operation. I know that there’s a Colostomy Association always asks if people will do this, but I just like everything else put it aside, put it aside. But my reaction I repeat, if I can *help anyone at all*, in any situation as far as counselling people, okay”. Most patients recognised that their restricted lives made them part of a community of disadvantaged people who could only relate directly and with belief to those who had undergone similar experiences.

One patient prided himself on the fact that his level of physical activity was as high as it had been before his illness. He made a major point of comparing his activity level with that of others with the disease, emphasising once again a recognition that his response was above the “normal”.

## DISCUSSION

### *Transparency and the non-transparent*

We believe that these three themes are developed as the person confronts explicitly certain physical and mental phenomena that are usually transparent (Leder, 1990). In our daily activities, we live with existential phenomena which are transparent to us, our vegetative functions, our taboos, and our mortality. Our hearts beat, our lungs pump air, our bowels process food, we walk, bend, stretch without special awareness of these basic functions. We live with taboos – bowel movements, menstruation, sexuality – which we do not usually discuss because we do not have to discuss them. At the cognitive level, we live also with our mortality ahead but unremarked, with the implicit knowledge that we will grow old, experience illness, dying and death. All these transparencies concern the functions, cognitions and fate of the body.

Any illness renders visible in some degree some thing or things that were transparent before the illness or its diagnosis. The cold blocks the transparent nose. Pneumonia brings breathing to consciousness. Bowel cancer may make the gut evident. A colostomy brings

reminders of bodily functions that we know and never discuss. Sometimes the diagnosis alone may render mortality visible, forcing a confrontation with a spectre whose presence has been acknowledged, but as “far off”, as “not yet”. The man with mild prostatism who learns that he has prostate cancer, and the woman found to have breast cancer on a screening mammogram are at once placed in this category. Most importantly, the diagnosis of serious illness brings about a confrontation with the self, with its meaning, with its slender grasp of autonomy, its obsessions and dependencies (Cassell, 1991). The transparent becomes the opaque, disturbing the view, demanding detours, demanding a going-out-of-the-way. These are detours which are demanded, not chosen. It is the malfunction and mortality of the body that demands these detours. The illness trajectory is mapped against changes in the way the body works and manifests itself.

### *Liminality*

Kleinman (1988) has documented the apartness of the seriously ill with particular clarity in his work on illness narratives. He comments specifically that certain illness labels “...encase(s) the patient in a visible exoskeleton of powerfully peculiar meanings that the patient must deal with, as must those of us who are around the patient” (Kleinman, 1988, p.22). Good et al. (1994). have also examined the specific way in which therapeutic “employment” needs to be structured around the particular boundedness of the time that may be available to patients with cancer. We believe that this sense of difference can best be understood in a way which we think is relatively new in medical thinking, although Leder has formulated something similar with his notion of “dysappearance” (Leder, 1990) and both Frankenberg (1986) and Murphy et al. (1988). have used the term in related ways. We believe that the state into which the survivor of serious illness, or the person with chronic illness, enters is one of *liminality*, and that this state persists in some form or other for the rest of the patient’s life. It resembles the state referred to as membership of the “remission society” by Frank (1995, pp.8-13). “Liminal” is a term familiar in neuropsychology, where it refers to stimuli of threshold strength at which a response will just be evoked. “Sub-liminal” became a vogue term some years ago to describe certain propaganda and advertising techniques. In the present sense, however, liminality is a concept adapted from social

anthropology. It was used by van Gennep in 1909 (1960), in his study of rites of passage. To van Gennep, rituals marked a process of passing through a phase of social evolution. During a period of separation from the rest of the society, the person was prepared by purification. This phase of separation was followed by a phase of transition, when the initiate had left their former state, but not yet entered the new one. In the third stage, the stage of aggregation, the initiate was accepted to full membership of the new status. The second stage of transition, van Gennep termed *the liminaire*, meaning “of the threshold”. The term liminal, in the present context, is derived from this.

Turner, (1979) elaborates liminality, particularly in relation to ritual and performance. He explores the concept of ritual and drama as “public liminality”. He defines the liminal as a space “betwixt and between the normal, day to day cultural and social states” (Turner, 1979, p.94), a particular space in which rituals and dramas may be enacted which serve to reverse individual roles or social status. In these events, time itself becomes liminal, as does the identity of those taking part in the performance.

In the context of illness, two formulations of liminality have been offered. Frankenberg (1986) followed Turner in using the term to describe periods of disruption of life by illness, in which structure and routine were abandoned. Murphy et al. (1988) used the term to describe the social view of the state of being of those with chronic disability (paraplegia or quadriplegia), a state in which their being was judged as “clouded and indeterminate” (Murphy et al., 1988, p.238). For Murphy, as for us, liminality categorises processes rather than phases or episodes. Whilst our notion of liminality is linked to these earlier formulations, it remains distinct from them. Unlike van Gennep, we do not conceptualise the liminal as a demarcated tripartite process. People who experience chronic or life-threatening illness do not necessarily pass through phases which can be neatly defined as (1) separation, the acknowledgment of the disease and the subsequent diagnosis which renders the person distinct from others; (2) the liminal; and (3) reincorporation or resolution back into the fabric of society. Nor do we necessarily draw on Turner’s or Frankenberg’s notion of the liminal as a phase or space in which the everyday can be inverted. Our liminality is an enduring and variable state. Further, unlike Murphy et al., we do not feel that it is necessary to have a clear and persistent disability to experience

liminality as a long term existential state. The labelling inherent in the cancer diagnosis is sufficient to induce and maintain liminality. Finally, our notion of liminality attempts to capture something of the nature of the subjective experience of illness, rather than to categorise the changes in social relationships inherent in being ill.

These differences arise from the nature of our problematic, which is to explicate liminality and the liminal state that people enter when they are given a diagnosis of serious illness, particularly a diagnosis of cancer. We believe that liminality is a fundamental category of the experience of serious illness that needs separate recognition and examination in any account of serious illness, whether or not it is associated with physical disability. We believe, furthermore, that the liminality of serious and chronic illness is experienced in two stages – an immediate phase of acute liminality, and an enduring phase of sustained liminality which may last for the rest of the patient’s life.

#### *Signposts to liminality*

Frankenberg and Murphy *et al.* are not alone in recognising forms of liminal experience in illness. Leder has recognised that the coming to awareness of the body, a phenomenon he calls its “disappearance”, is alienating, confronting and incommunicable to someone who has not shared the experience (Leder, 1990). The same point has been made by Toombs (1992), within a phenomenological model of illness. Our own concept of liminality differs somewhat from these conceptions because it considers the response to be a dynamic, reflexive process, constructed and modified dialectically within the locus of embodiment throughout a lifetime. Liminality is also familiar in other contexts. Existentialist philosophy and the history of attitudes to death and dying both provide insights into its nature.

*Existentialism and liminality.* If there are themes that unite those labelled as existentialists – thinkers as widely diverse as Kierkegaard, Heidegger, Marcel, Sartre, de Beauvoir, Camus and Merleau-Ponty – it is their view that liminality is the mode of life in which we must live. Macquarrie comments that one “... group of existentialist themes includes such topics as finitude, guilt, alienation, despair, death” (Macquarrie, 1973). Kierkegaard’s angst, Heidegger’s dread and Sartre’s anguish, vertigo and nausea are conditioned and maintained by the sense of absurdity inherent in human being. We come from nothing; to nothing we return.

The certainty of death, according to Heidegger, is the fundamental confirmation of our existence in the world. “This certainty”, he writes, “that I myself am in that I will die, is the *basic certainty of Dasein* [being-in-the-world] *itself*... The MORIBUNDUS *first gives the SUM its sense*” (Heidegger, 1985, pp.316-317). Sartre writes that “Anguish is precisely my consciousness of being my own future, in the mode of not-being” (Sartre, 1977, p.32). “Not-being” has several meanings for Sartre. While it carries the meaning of extinction, it also carries a meaning of negation. By appreciating what we are not, we come to understand how we may exert our freedom to choose, to create ourselves as we will. This freedom is the existential challenge, but it is a freedom which functions within our sense of boundedness, of the inevitability of death. “The movement of fright, expressed as vertigo and shuddering, becomes, in anxiety, the turning point where I become conscious that I can be annihilated” (Jaspers, 1986, p.112).

This same preoccupation with boundedness also appears in Heidegger, as it does in Kierkegaard. For Kierkegaard, the human condition is so absurd, so devoid of meaning and reason that it can only be lived by those who accept the inadequacy of reasoning to provide a reason to live and make “the leap of faith” which affirms the incarnation of God. Such a leap of faith is not rational, nor can it be made by reference to others. It is something to be done by the autonomous individual. It alone can achieve the “ethical reality that should mean more to a person than “heaven and earth all that therein is”, more than six thousand years of human history” (Kierkegaard, 1941, p.305). Further, the leap of faith must be made and made again, because life has to be lived permanently challenged by a future of groundless choice. For anyone living in a liminal state, “life must be lived forward, but understood backwards”.

The apparently gloomy challenge of existential thought had a period of enthusiastic support among Western intellectuals, particularly in Sartre’s time. As a “philosophy of life”, its recognition of validity of dread, anxiety and angst resonated with the mood of many Western intellectuals after the Second World War. Existentialists distinguish fear from dread by following Kierkegaard’s formulation of fear as an emotion focused on something, a perceived threat. Dread is unfocused, or, in Sartre’s terms, the emotion that recognises Nothing as its object. This sense of nothingness encapsulates, for Sartre existential experience.

Most of us do not carry this dread in the forefront of our minds, nor do we live each day with fear of dying. But these existential emotions are evoked when the transparencies of bodily function, of mortality and of the strategies around which we have constructed our lives are suddenly made visible by the diagnosis of cancer – or any serious illness, for that matter. Then we confront the fear of dying, of pain, of decline and degradation, and the dread of the nothing into which we apparently go. This is a part of the experience of liminality. For the cancer patient, it can be coped with, it can be palliated. But for the reasons we have already mentioned, it cannot be completely removed. Each medical visit is a reminder of the non-transparency that began the process. The liminal life is also the existential life, separated from other lives only by the symptoms and disabilities of the illness, and a cultural agreement to validate the transparency of the existential issue in times of “normality”.

Further, there is a cultural endorsement of certain attitudes in liminality. Sontag (1991) has written about the metaphors we use in talking and writing about cancer and AIDS. They are often military or political. Cancer invades, infiltrates, colonises and spreads, it overwhelms the defences of its host, who wins or loses the battle against cancer. Putting up a good fight is socially endorsed. Patients will often say, when someone explains that there is nothing that can be done to cure the disease, “I can’t simply give up. There must be something I can do to fight this thing”. Relatives and friends will say in hushed (and often slightly disapproving) voices, “He’s given up. He just doesn’t seem to want to fight it any more”, as though the effort of will could indefinitely prolong life.

It thus appears that liminality brings an existential vision, with its fears and dread. At the same time, it imposes a role on the sufferer. At that moment when a person may need to make a choice that might achieve what Heidegger calls “authenticity” (Heidegger, 1962, pp.290-293), social constraints may demand a prescribed course. This battle for authenticity can be seen in the contrasting narratives of death written autobiographically by Ingelfinger (1980) and Broyard (1992). Ingelfinger was a great physician who died of stomach cancer. Almost to the end of his illness, his colleagues expected him to remain a clinician to whom they would defer. Ingelfinger sought advice and support, and was reduced almost to despair by the expectations of his colleagues. Broyard died of prostate cancer. During his



illness, he retained a lively, critical interest in all that happened, and in the ways that doctors perceived and managed his liminality. He reconstructed his own experience in terms of his own biography. This difficult process of looking backward to make sense of a life under the shadow of its boundedness, and of confronting the entropy of the future is made more complex by the restriction of approved roles. There is little wonder that the experience of liminality is so unsettling, nor that families and friendships are so important and so deeply challenged by liminality.

*Liminality as historical normality.* While we can never recapture the experience of and attitudes to episodes of illness within other ideologies of health, past and present, there is indirect evidence from historical documents and literature which give us some understanding (Ariès, 1976; 1991). Liminality may have been the “normal” state of human existence for the greater part of human history. The non-liminal existence is a creation and ideal of modernity, and postmodernity’s deconstructions seem to have left the non-liminal ideal untouched. Only existentialism seems to have recognised that the liminal view has to be included in any satisfactory account of the experience of life.

In earlier times, illness was a part of the irregular, unpredictable life trajectory, a part of the earthly experience, along with birth, death, war, famine, epidemic, worship, labour, persecution and so on. For the common man, the most that could be hoped for was a tenuous prosperity in a trade or profession. Illness was simply a part of the profile of risk, to be endured with the help of family, traditional healer, priest or physician. If one survived, one returned to living as before as best one could, surrounded by the same risk profile. Illness was an episode in “normal” life, like fighting wars and working for a living.

The era of biomedicine and biopower (Foucault, 1978), however, has introduced a new paradigm of illness. It is no longer an episode in normality, but an abnormality in a life trajectory which is supposed to be smooth. Illness is an aberration to be engineered out of existence by a monolithic system of enormous complexity, power and cost. The episode of serious illness is now a *thingsui generis*. It takes the ill person away from his “proper” sphere, and passes responsibility for his or her continued existence and for the shape of his life trajectory to another agency. For the unique embodied Me, illness is no longer purely a part of my ordinary life, but a social event for which I am only in part responsible. If

I am seriously ill, I am in the hands of a system which I have endorsed and supported in many ways, but a system which functions each day without regard to Me as an individual. Its daily regard is for other examples of my bodily disease.

Illness therefore confronts me with my mortality, my meaning (or lack of it), with the values which sustain my society (and which are otherwise largely transparent to me). It places me, in other words, in the state of liminality, and allows me to share, without knowing it, something of the experience of my forefathers who lived before the era of biopower. They balanced their profile of risk with tradition (which gave them links and continuity with their past), close bonding with their families and social circles (which gave them a place in the present and some assurance about the future), and religion (which gave them some promise of a future beyond the disturbing boundedness of life) (Giddens, 1990). These coping mechanisms should be seen as neither good nor bad. It is pointless to regret their passing, and their current unavailability if we feel that they have no contemporary relevance. What is especially poignant, however, is that there may be no such mechanisms currently available for the ill person who enters a liminal state, which would have been a part of the “normal” experience before the era of biopower. This is another element of the experience of liminality, the experience of being lost in an unassimilated heritage. Coping with this sense of being lost now needs the services of counsellors, psychologists and therapists, supplied by the system which creates and maintains the modern alienation from liminality.

#### *The nature of liminality in cancer*

The telling and the hearing of news of serious illness suspends meaning, challenges beliefs and confronts us with the boundedness of our time and space. Kleinman expresses this clearly when he writes (Kleinman, 1988, p.20):

Cancer is an unsettling reminder of the obdurate grain of unpredictability and uncertainty and injustice – value questions, all – in the human condition. Cancer forces us to confront our lack of control over our own or others’ death. Cancer points up our failure to explain and master much in our world.

The moment of suspicion of the diagnosis is the moment when one enters liminality. The experience of liminality involves all the responses to serious illness, such as fear, hope, anger, shame, rejection, suffering, pain and dispossession. The liminality we enter with the diagnosis of potentially fatal illness sets us apart from others. Images of death are with everyone all the time in literature, film and television, but death socialised by its imagery, death meted out to wrong-doers, noble death, defiant death, trivialised death, sanitised death. We tend not to dwell on the reality of our own death.

There are at least two stages of liminality in the cancer experience. There is an initial phase of “acute liminality”, when the patient hears the news and experiences the existential threat and its fear and dread. Acute liminality looks like a “black box” to the outsider. The autonomy level, cognitive performance, physical and social capabilities and psychological state of the cancer patient and her symptoms enter the black box of the acute liminal state and emerge much modified after a variable period, whose length and intensity depend on the biography and natural endowments of the patient, the nature and strength of her support groups, the nature of the medical news and the impact and outcome of treatment. Acute liminality represents a discontinuity of subjective time, in which powerful forces operate to change perceptions of time, space and personal values. It resembles the singularities in space (such as “black holes”) which Hawking (1988) writes about, within which time and space no longer obey the familiar rules that we expect of them. The outputs of the acute liminal state are hard to predict with any certainty, and the processing devices within it are poorly understood.

Sustained liminality follows the acute phase after a variable time. Patients begin to enter it as they reach the convalescent phase, and begin to reassert control by the small acts of independence noted by our narrators. These gestures may sometimes appear to be acts of non-compliance (Fogarty, 1997). In this phase, the patient remains aware of their cancer-patient status, the alienation that comes from the diagnosis and the difficulty of communicating the nature of the experience of illness and treatment, and a sense of boundedness in time, space, work, power and social functioning. Even in the phase of sustained liminality, the trajectory of subjective experience moves at times toward the disturbances of the acute stage, and at others toward a kind of resolution, depending on the medical news, the

fluctuation of symptoms, the presence or absence of support and countless other incidental factors. Frank confirms this oscillating trajectory from his own experience (Frank, 1995, p.136). We believe that aspects of the liminal state last as long as the life of someone who has survived cancer. It is likely that the same may be said of any life threatening illness or chronic illness. Our observations suggest that sustained liminality can be understood as a prolonged dialectic between body and self, in which a narrative is constructed to give meaning to the challenging and changing biographical, physical and existential phenomena in which illness and aging evolve in the locus of the body.

This model considerably modifies our understanding of the illness trajectory (Robinson, 1990; Woog, 1995). The iterative nature of the medical follow-up process needs to be accommodated, because it reflexively modifies the process in the light of its own development. Patients look ahead to the next medical appointment, knowing that the news may not be good. At the clinical encounter, they will be asked to look back at the time since the last appointment, so that symptoms of significance can be coded by the health care worker. Signs will be sought and tests carried out to compare the present with the past. The general direction of the trajectory can be charted, but its components may become dissociated. At one visit, there may be less pain, but greater weakness, less appetite but greater calmness. Iteration and the compound nature of the trajectory makes its modelling complex, although not impossible.

Thus, iteration within a medical system becomes a part of the rest of life for many cancer patients, and is emphasised in our narratives as a source of recurrent anxiety and a reinforcement of the state of cancer patientness, in the same way that Frank has described (Frank, 1995, p.136). People who have had cancer remain identified as people who have had— and perhaps “beaten”— cancer, but few of them can forget, and many are regularly reminded by their surveillance or screening programmes. They enter, along with sufferers from chronic illness and those who have survived serious threats to life, a phase of sustained liminality, in which adaptive mechanisms are repeatedly formulated and reformulated.

These experiences of liminality are expressed in the three themes of cancer patientness, communicative alienation and boundedness in the narratives of our cancer patients. The themes should not be seen as wholly independent of one another. They are indeed mutually

interdependent and reflexively reinforcing. Thus, reminders of cancer patientness are reminders of boundedness. Experiences of communicative alienation reinforce the sense of cancer patientness. To experience the hostility of the non-transparent body is to confront boundedness in time, space and social context, and to be reminded of one's cancer patientness. The three themes thus overlap, shift and elide in a process which begins in the high drama of acute liminality, but which persists life-long in the repeated rewriting and re-ordering of the illness narrative. The experience of liminality, both acute and sustained, is, in short, the experience of confrontation with the implications of embodiment. To perceive the limitations of the body, to experience the body as dread, as unfamiliarity, as the non-transparent, is to experience alienation of the self from the vehicle for self.

## CONCLUSION

The subjective experience of illness is poorly reflected in most current models of health and disease used in the practices and policies of medical and health institutions. This deficiency is seen by the ill as a serious problem (Broyard, 1992; Toombs, 1992). The illness experience is enormously complex, varied and many-faceted. We believe that the notion of liminality provides further insight into this experience. There are three reasons for making this claim.

First, liminality captures what is told in illness narratives (Frankenberg, 1986; Murphy et al., 1988). Narrative is a universal means of communicating the richness of experience generally. It is therefore probably the best window we have onto the subjective experience of illness. More broadly, narrative is the most common and widely occurring means of human communication, and it is used daily in the sciences, politics and the arts.

Narrative is, therefore, the most likely source of communicable understanding of subjective experience. Liminality provides a category of understanding of the dynamic processes of accommodation and adaptation that the ill experience during their illness trajectory and express in their narratives. It is a concept which preserves the importance of individual experience, while offering a broad and flexible interpretive framework within which to understand that experience.

Second, the notion of liminality grounds illness firmly in the central fact of its embodiment. This is clearly

crucial to the context of medicine, but remains important in social and political contexts because it is central to the illness experience. The tendency to concentrate on disease as it affects organs and systems and to neglect the embodied suffering that illness produces makes it easy to neglect non-medical insights which are important in understanding illness. The concept of liminality preserves the link between medical discourse and individual suffering by way of the body. This makes the concept powerfully translatable into clinical knowledge and practice.

Third, it is clear from documents like those of Toombs (1992) and Broyard (1992) that patients and health workers experience serious difficulties in communicating with and understanding one another. Categorisation of illness experience provides an instrument for education which may help health workers to understand what patients experience, and why they behave as they do at particular times in their illnesses.

For these reasons, we think that the development of understanding of liminality is of both theoretical and practical importance. We believe it to be a significant contribution to the cartography of illness.

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