

**On Producing and Reproducing Intensive Care:
The Place of the Patient, The Place of the Other**

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2007

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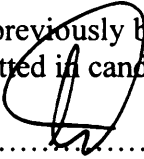
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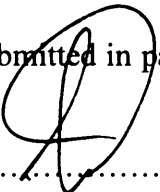
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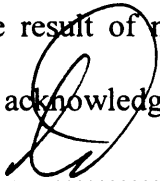
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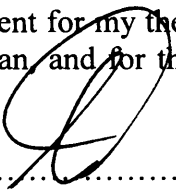
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Abstract

This thesis traces ideas of visibility; how certain social practices can be made visible and how other practices are obscured. Beginning with ideas concerning ontology and epistemology, the thesis explores how through the production of ethnography, epistemological positions can be made visible, and how through the doing and writing of ethnography, an attempt was made to make certain positions visible within a context of performing ethically grounded research. A background is laid, demonstrating competing perspectives of what constitutes intensive care; historically, publicly and within the context of the field. The main body of the thesis shows how these common sense and historical understandings are made visible within the everyday social practices of intensive care and are reproduced through interaction, documentation and the treatment of patients.

Issues surrounding performing ethnography within an intensive care unit were treated as problematic by the Local Research Ethics Committee. This made visible that which constitutes legitimacy; how legitimacy is granted, its requirements and the place of the individual. Failing to meet the criteria of legitimacy can lead to processes of disposal. Disposal is demonstrated to be aligned with processes of 'othering', not just within systems that are designed to protect the public, but are an active component of individual lives and of securing admission to, or discharge from intensive care. The thesis examines social life within intensive care from multiple positions and as a consequence positions intensive care as a particular cultural accomplishment. It is through such accomplishments that the patient within intensive care is made visible and conversely it is from the perspective of the patient that organisational processes can themselves be seen as a specific cultural accomplishment. This thesis represents an examination of accomplishments, of invocation, alignment and disposal through which, tacit cultural assumptions and the position of the patient is laid bare.

Acknowledgements

Of the hundreds of people I should thank for enabling me to produce and perform this research, some stand out as particularly worthy of note.

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**On Producing and Reproducing Intensive Care: The Place of the Patient, The
Place of the Other.**

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Chapter One.

Introduction (or *apologia*): Part One and Two.

The first ethnography: an anticipatory introduction (part one)¹.

The following research examines how a sense of self and self-identity (Goffman, 1959; Giddens, 1991) can be challenged by the experience of critical illness, and its treatment within the intensive care unit (ICU). Whilst there have been studies of the disruption of identity resulting from chronic illness, these do not take account of the compounding effects of intensive technological treatment and critical illness on participation, sense of self and the performance of identity. Importantly, within the ICU the critically ill are not just subject to the *biographical* disruption (Bury 1982) of a critical illness. Rather in ICU the patient is temporally and spatially dislocated through use of sedative anaesthetic agents whilst made speechless through methods of intubation. Thus in ICU the patient is subjected to physical immobilisation in time and space and temporarily *rendered* socially 'dead'. While the immediate effects on patients, such as extreme anger and disorientation on being 'woken' have been reported, the effects of these treatments in addition to the social organisation of the ICU on patients sense of self and identity over time, have not been thoroughly investigated. Drawing together a critical ethnography of the ICU with longitudinal biographical interviews among survivors of ICU treatment, the study will examine the unintended consequences of the social organisation of intensive care, exploring the specific social and personal consequences of critical illness, and its associated treatments, for patients and their families.

There is increasing recognition of the need for follow-up services for patients after having received treatment in the ICU, both on a political (Audit Commission, 1999; DoH, 2000) and professional level (Waldmann, 1998). Following discharge from the hospital, patients receive little or no support (Russell, 1999) to deal with what can become a chronic illness (Griffiths & Jones, 1999; Waldmann, 1998). While it has been recognised that once the underlying illness has been treated, there are specific ICU related psychological problems such as Post Traumatic Stress Disorder (Jones et

¹ This is a synopsis of the initial research proposal submitted to the Local Research Ethics Committee (2003).

al., 2001), Acute Stress Disorder (Vick & Roberts, 2002) and depression (Perrins et al., 1998), these have not been explored as the possible effects of disruption to self and identity. Thus, the current research explores how the ICU is organised and practised, and what relationship this has to the experience of the patient and their families. Although studies of this type have been conducted previously (Seymour, 2001; Zussman, 1994), they have not traced the experience of those who have been through intensive care, and on through recovery and discharge. Findings will be used to recommend approaches to assessment of need and methods of follow-up that take account of potential difficulties relating to personal and social reintegration.

The study draws on interactionist and anthropological insights into how a sense of self and identity is accomplished through *participation*. However the study also recognises that participation and sense of self are mediated through particular power effects (Latimer 1999) and by the conditions that *embodiment* imposes (Savage 2000). This study, therefore, relates patients' experiences of ICU therapy to both the organisation of intensive care and subsequent follow-up. Interpretative ethnography (Denzin, 1997) will be used to create a detailed description of ICU work and social relations. The immediate and longer term implications of treatment and care within intensive care will be contextualised using narrative biographical interviews (Bury, 1982; Williams, 1984). This investigation, drawing upon some themes developed from a pilot exploratory ethnography (White, 2002), aims to explore the consequences of ICU therapy, intended or otherwise, within the context of the survivor, and over time. This is of particular significance to contemporary nursing and health care given the political motivation to reform critical care, at a time when so little is actually known about what patients actually experience following discharge, particularly over 12 months. Significantly, this represents a piece of research that has pertinence within health care policy and practice, contemporary society, and of course intensive care patients themselves, that has not previously been undertaken either within the UK, or indeed elsewhere.

As it stands: 'laying out' a thesis: an introduction (part two).

Within hospital, and indeed hospice life (Lawton, 2000), 'laying out' or the performance of 'last offices' are the final act of dealing with a cadaver prior to

transfer to the mortuary. It is the moment in which (predominantly) nursing staff wash the dead body in preparation for its move to 'Rose Cottage' or 'the eighth floor' of a building that has seven floors, a romantic and metaphysical euphemism for the mortuary, whilst symbolically preparing the body for whatever happens once life is extinguished. In this light, the previous introduction is a 'laying out' of the research that was not conducted, a settling, a finishing and a disposal.

The previous introduction, 'an anticipatory introduction', was a summary of what the thesis was intended to be about and could be seen as an idiosyncratic residue of a piece of research that never made it to fruition, not at least in the ways in which it was intended. However, it remains as a means through which many aspects of the research can be understood, without which the thesis would have a slightly different meaning. It is through its inclusion that some of the unwritten, tacit and taken for granted aspects of the research become more explicit. On account of its presence there is a recognition that research evolves through its performance and requires a certain adaptability to survive, at least in this case. Without it, the thesis becomes a supplement (Derrida, 1976) to it, something left unspoken, unreferenced or unwritten. It has a point of reference that is never made explicit; paradoxically it both exists as something hidden yet does not exist because it is not alluded to. It is both effaced yet a major part of the thesis without which the meanings would be quite different. For it to be omitted would be to misrepresent what the thesis is about, even though the thesis no longer has the same concerns. A form of violence would be performed on the original intent in its omission; to keep it could be read as a form of resistance. Either way, to have as a major part of the research something alluded to but never admitted just does not seem to be the way the thesis should be constructed, the sense that would be made would alter. Its inclusion is also its death in some way, a recognition of its non-inclusion, whilst it permeates the present it is at one and the same time, not present, the act of disposal creates the possibility of its return. As such it is included as a sort of 'last offices' a farewell, it is being laid out, washed, purged and sent to a non-existent floor of the building. The rituals are performed so that the new thesis can emerge and for now a description of the layout of the thesis can be made, a thesis with an origin in something that now only partially exists, and to which the current thesis is partially connected (Strathern, 2004).

Having 'laid out', metaphorically, the body of an intended thesis, the structure of the current (present) thesis needs to be 'laid out' to provide some insight into what may be expected as part of the research and its representation. However, ghostly remnants, broken appendages of that which were intended in some part remain (Derrida, 1976; 1993). But there is only so much playing with words and metaphors that can be done before it is necessary to set out quite what the research actually does or purports to do.

The next chapter (Chapter Two) aims to sketch a theoretical position from which the research takes its shape. So far, some of the tacit assumptions that have informed the thesis have been made visible, not so much because they have a concrete bearing on what the study examines, but because they have a base level of influence on how the study has been conducted and the route which it has taken. Similarly, within some forms of research, the epistemological positions remain obscured, hidden from view, unwritten, they refer to a way of seeing that is significant in the analysis but remains out of view. Approaches are taken in which a particular research method is seen as 'the best tool for the job', with little attention paid to some of the assumptions that underpin that 'tool'.

The conduct of research itself is a highly political, and politicising, act that should not be divorced from the position from which the research arises (Gouldner, 1971; Wilkinson, 2005). The research area that is under scrutiny, through the use of a certain method, is not as clear-cut as a metaphor of 'the right tool' would suggest. To use one method over another can be read as a political statement in as much as the underpinning knowledge or knowledges are based upon certain political assumptions. In some ways the adoption of a particular method, which can hold assumptions of a particular ontology (Gouldner, 1971) have the effect of legislating the legitimacy of the research terrain, which in turn delineates the interpretation of the research (Bauman, 1987). That is, the means through which the research has been approached, or legislated for, returns in the means through which the research is interpreted. The limitations of the research, the conditions of the research and the boundaries of the research have been legislated and these issues return within the interpretation of the research. Holding the joint role of both legislator and interpreter emphasises, in part, the recursive constructions of culture and modernity (Giddens, 1986; 1991), reflecting a given moral order and ensure that those with the power to veto research can ensure

the status quo, such as maintaining the dominance of a particular way of seeing and acting in the world. The metaphor of the tool can be seen as a means through which the findings of the research reflect the underlying ontological position of the researcher. The way in which the research is approached dictates the implications of the research within a recursive, self-regulating system of simultaneous legislator and interpreter (Bauman, 1987). In this sense, research cannot be seen as beyond the political, as the system of performance reflects and is part of a way of establishing order, the research is, as such, political. This leaves the issue of how research can or should get beyond this and perhaps through Gouldner's (1971) notion of domain assumptions, a possible means through which the research and its conduct can take a step away from not only legitimising itself, but the more pernicious consequences of the production and reproduction of cultural oppression.

What I do believe is important is that some of these theoretical and by implication political assumptions are made explicit, showing where its limitations are from the outset, embracing the difficulties that this form of research brings upon itself through its recognition that research is not an apolitical act. This becomes at one and the same time its major strength, in that it is open to criticism and a deeper level of analysis, which is simultaneously its greatest weakness. For the context of this thesis, these knowledges are a partial representation of what constitutes intensive care, it is a view put forward by a single author who uses the words, actions and meanings of others to create an idea of what it is that constitutes intensive care. Certain positions and perspectives are held as legitimate through such representations and as a consequence are a major thread throughout this thesis as a whole. It is through this recognition that the importance of theory and the recognition that it is an individual position become so important. So Chapter Two opens with some of these issues that I felt needed to be addressed from the outset.

In addition some of the key themes of the thesis which concern the means through which certain cultural performances are held as legitimate. A preliminary insight into some of the major tropes and concepts that thread back to legitimacy will be presented. The means through which legitimacy is produced and reproduced in relation to cultural materials and cultural artefacts through practices of invocation, alignment and disposal will be touched upon. These issues feature in numerous guises

as major tropes that hold the thesis together. To close Chapter Two, an account of gaining access to the field will be presented which draws upon such cultural; understandings.

As there are assumptions concerning epistemology, there are also assumptions about how intensive care is constituted. Chapter Three provides some insights into *how* intensive care (or perhaps more accurately the staff that in part constitute intensive care) defines it and *where it defines itself from*. Differing slightly from most historical accounts, the aim is to get to grips with competing discourses of what constitutes intensive care in relation to certain events in the development of intensive care. Intensive care professionals and those involved in tracing its origins have a key event in mind when explicating the origin(s) of intensive care. However, it has been highlighted elsewhere (e.g. Fuller, 2006) that only certain aspects of a given history are presented, with many wrong turns and blind alleys being silenced or omitted (Latour, 1987, 1991). Further, what makes and counts for history is in part a retrospective legitimation and the representation of that deemed legitimate.

This omission in turn provides telling insights, through the analysis of key moment(s) of what actually is *held* to constitute intensive care. As Latour (1991) weaves a narrative of the Kodak camera and the mass market through a socio-technical path, so intensive care can be read as a socio-technical innovation. Importantly, through the durability of intensive care as a concept and its origins being presented as neatly tied down to a single historical event, an insight into what constitutes intensive care comes to the fore through this established, durable event. Intensive care becomes located and defined in relation to this moment, having implications on how it is constituted and lived by intensive care staff and those other hospital staff that work around them. However, there is more to the development of intensive care than this single event and through readings of multiple factors outside of intensive care these can be illuminated, perhaps leading to competing ideas of what constitutes intensive care. It is through these material and cultural relations that the place of intensive care and indeed more recent policy developments can be understood. In explicating certain histories of intensive care and the discourses associated with its own defining moment an insight can be presented into a particular history's durability and its relation to intensive care in the present.

This leads on to a brief outline of how intensive care is figured by the media. Through readings of newspaper headlines and popular fiction, a perception of the cultural meanings of what constitutes intensive care can be made explicit. The explication of how intensive care is figured within the media enables insight into what constitutes intensive care and how it is understood as a cultural artefact. For the most part, ethnographers of intensive care (or indeed ethnographers more generally, but particularly in health care) are not overly concerned with how a cultural space is figured within popular imagination, particularly when popular perceptions are not the main focus of the research. Instead readings of intensive care centre around power, decision making, passivity and the dominance of the technical. While I recognise that many of these things are at stake, with regard to intensive care in order to develop an insight into how intensive care as a distinct site is culturally produced and reproduced some examinations of how it is being invoked as a particular metaphor is useful (Lakoff & Johnson, 2003). In part intensive care as metaphor emphasises the serious nature of a given situation that requires intensive care and is of great significance in detailing intensive care as a particular critical site within the popular imagination.

Additionally, a presentation of cultural representations (Clifford & Marcus, 1986) of intensive care provides a context from which the site can be reproduced ethnographically. Of course, these are partial explanations of the construction of intensive care as, it could be argued, is any ethnography. However, despite the fact that most people have not had very much contact with intensive care, this does not appear to alter the potency that the invocation of intensive care within popular usage actually holds. As such it is felt to be of great significance for a cultural context to be (re)produced from which a thoroughgoing analysis can be made about what intensive care accomplishes. Particularly as those within intensive care are themselves a product of the culture that invokes it as a particular metaphor.

In this respect, having laid down a background to the cultural scene of intensive care, through the tracing of its evolution and through the cultural representations that refer to it through the popular media, the thesis does not follow the traditional structure. In some small way, readings of intensive care can be seen as a broader recursive dimension of culture (Giddens, 1987). In this sense, the thesis partly follows this recursive dimension, but more accurately, perspectives shift through the course of the

thesis in order to illustrate competing forms of cultural accomplishments (Garfinkel, 1967).

The conventional literature review has been foregone in favour of a more detailed cultural analysis of what constitutes the site within its own terms and within the terms of a popular consciousness. This provides a context from which the accomplishments of intensive care as a particular cultural space can be read, that is those distinct aspects of intensive care are not reproduced from a specific review of the literature surrounding intensive care. While this is as significant as a background literature review, it is more significant as a mode of analysis, to use the state of knowledge as a means through which the cultural space can be critiqued. However, whilst this will be achieved to some extent, the issue remains that these readings of intensive care have their own bias and agendas and, arguably, could be read as a product of the consumption of intensive care as much as any other cultural material (Derrida, 1976; Munro, 1996; 2001; Hetherington, 2007). The intention is to provide an in depth description and analysis of intensive care in its own right from a particular local site which may or may not be generalisable to other sites.

Where this ethnography differs from those which have gone before that concern decision making (Zussman, 1994), death and dying (Seymour, 2001) and its comparative organisation (Cassell, 2005) lies in its focus on the mundane and the ordinary in a site characterised by drama. Focussing on the taken for granted, the means through which culture is produced and reproduced can be made visible. Whilst it is recognised that Zussman (1994) touches upon this in relation to the notion of the 'banal heroism' of intensive care practices, it is its form in the smaller, tacit and taken for granted that this research differs, away from the representations of medical decisions examined from the perspective of the intensive care Ward Round (Zussman, 1994).

From this point, the background to and problems of ethnographic research is outlined within Chapter Four. There are particular issues in performing research within intensive care, such as speechlessness and unconsciousness and an elaboration of these issues are made. This chapter then moves on to some considerations of the uses of specific forms of ethnographic methods, with particular reference being made back

to the epistemological positions outlined within Chapter Two. A particular aspect of the research was to not divorce the ontological from the epistemological as this is a position that theoretically I felt to be of great significance. One of the means through which this was to be achieved was in relation to performative reflexivity, which is felt to be internally consistent with the theoretical position outlined within Chapter Two. This was originally envisaged to circumvent any potential ethical problems within intensive care. However, it brought forth new unintended issues with regard to the research, which are also outlined. This leads to a specific description of the way in which the research was conducted within intensive care and the methods that were used to collect the ethnographic materials.

Once the methods of the research have been made explicit, the following chapter the first empirical chapter is presented. This chapter concerns the nature of ethics and gaining ethical approval. As a general rule, the ethics section would be a part of the methods section of the thesis. However, the sheer weight of the problems involved in receiving approval from the Local Research Ethics Committee (LREC) in the first place makes the issue a major part of the research and as previously mentioned has written itself into the thesis and as such receives its own chapter, Chapter Five. This chapter is largely an auto-ethnographic account of gaining ethical approval and has been included as a means through which the practices of the LREC are made visible. In some respects it represents a breaching experiment (Garfinkel, 1967) that demonstrates what aspects of qualitative research are deemed legitimate and particularly the means through which legitimacy needs to be represented in order to secure approval. In this sense it ties in with broader themes of the research as a whole which traces aspects of legitimation and representation as a cultural production. Specifically, the broader theme concerns what and who is of legitimate concern for an intensive care unit, in terms of practices, knowledges and patients.

Having spent a major part of the thesis with only a small sojourn into the life of the critically ill, Chapters Six, Seven and Eight will provide an insight into the world surrounding the critically ill within intensive care. In many ways the intensive care patient is the focus of the ethnography, however, they are regarded in relation to the accomplishments of intensive care as a particular cultural space. This approach provides fresh insights not only into specific working and cultural practices, but aids

understanding of the multiplicity of issues that characterise intensive care as a critical site. This issue has a resonance with that of Chapter Three, which draws upon differing cultural representations of the space and place of intensive care.

Chapter Six is concerned with the unconscious body. It details what is known of the identity of the person in the bed and the multiple constructions of who that person is through recourse to, among other things, their reason for admission. It details the processes involved in securing admission (access) and significantly the process of transforming the body from the sick, to the critically ill. This aspect of intensive care work and its relations to the practices of documenting vital signs has been discussed ethnographically from the perspective of a Paediatric Intensive Care Unit drawing on Actor Network Theory (Place, 2000). Chapter Six differs in relation to the working of materials from that of Actor Network Theory. Materials, such as an observation chart which details patho-physiological 'representations', instead multiple interpretations are made upon those representations, as will become clearer. Intensive care technologies order the social world and impact upon the ways in which intensive care staff view the unconscious (or indeed conscious) body. The body is rendered legible through writing the body onto charts and, it is argued, the process impacts upon the gaze through which intensive care staff construct the body. Whilst from a Latourian (1987) analysis, this could be presented as a process of inscription, within the thesis the term legibility is taken as transforming the body through physiological interpretations in a way that makes sense to intensive care staff and as the legitimate means through which the body can be read. Suffice to say, the chapter is concerned with the legitimation and representation of admissions to intensive care, focussing upon the dealings with the body of the unconscious.

As Chapter Six has as its viewpoint the bed space of the unconscious body, Chapters Seven and Eight have at their core a quite different space for analysis. This space is an anatomical space, the space of the mouth and its position within intensive care. This anatomical space is associated with ambiguity and ambivalence. On the one hand within a culture that privileges talk, the mouth is a site in which the world around is constructed (produced) and reconstructed (reproduced) through speech and interaction. On the other hand it becomes a site of risk and pollution. As will be demonstrated, once the 'civilised' focus of the mouth, speech, is stripped of its

capacity to function, so the space becomes one of defilement, it is both sacred and profane (Douglas, 2002) becoming a political site of contestation. This issue whilst evident within other chapters is a particular focus here.

Chapter Seven focuses on everyday interaction and the engagement of the speechless within mundane social relations (Goffman, 1959, 1967). The social world is emphasised through those reflexive embodied acts of the everyday (Merleau-Ponty, 1962) and is made visible through the accomplishments of the critically ill. Chapter Eight on the other hand again refers to the mouth, but in relation to the powerful cultural effects that the mouth produces. Without speech other potent devices are used to circumvent the effects of silence which demonstrate the power of some of the taken for granted aspects of the spoken world. In part demonstrating the power of the individual (Rapport, 1997, 2003) to interact and become a part of a cultural space that could be seen as tightly regulating interaction. It emphasises the space of the mouth as a powerful tool that has an effect on social relations. Not just in relation to the spoken world but the means through which the speechless similarly use the mouth to communicate and when this fails other means are found to communicate with family members and health care staff. A picture is cast of an intensive care unit that is not all to do with passivity, but of active engagement in the social in spite of the limitations that intensive care technologies impose.

The final chapter aims to tie those aspects of cultural spaces, the heterotopias evidenced throughout intensive care as real-and-imagined spaces (Soja, 1996), together. It unites some of the ways that organisational systems construct the gaze in which intensive care holds and in turn becomes the means through which such specific policies are embodied by health care staff. This, it will be demonstrated, has a distinct impact upon the ways that patients, or in fact anybody who has contact with intensive care are treated and related to. The way that intensive care is conducted can be viewed as a specific cultural effect that has at its root cultural artefacts, such as health care policy, and made visible in relation to those cultural artefacts, such as the durable histories of what intensive care is held to be. The history of intensive care becomes a particularly durable technology to ensure that the cultural order of intensive care is produced and reproduced. Within intensive care, as previous ethnographies demonstrate (e.g. Zussman, 1994; Seymour, 2001; Cassell, 2005),

ethics and particularly medical ethics are a core part of the organisational workload. But these ethics can, and often are, invoked to legitimate certain actions. Ethics itself becomes a legitimating principle which governs. As will be demonstrated, the ethics as a consequence no longer has too much to do with what is right or wrong apart from in a symbolic form, but more to do with ensuring that certain actions are expedited, or more critically, are mobilised as a distinct means through which the workload of health care professionals are made easier. This has little or nothing to do with the welfare of patients. Ethics becomes a system of making life easier for health care staff and less appropriate for ideas of patient care, or indeed (moral) ideas of good and right.

It is through the examples of those patients in intensive care, that a given social or moral order of intensive care is made explicit. Significantly, when those actions performed by patients breach such an order, the boundaries and conditions of the order of intensive care are rendered visible. Similarly, through almost two years of attempting to secure ethical approval some cracks in another system, a system of ethical regulation becomes apparent. As the stages of securing approval developed, so did the strategies for ensuring such an approval was accomplished further developed on my part. In attempting to perform a piece of research which was felt to be as sound ethically, as it was epistemologically, in being open and honest about exactly what it was I was trying to undertake, the research failed. The effect of which was to produce less disclosure (honesty?) in the submission of research for review, to obscure issues that may appear to fall foul of such a committee. In turn, the proposal became increasingly obscurant according to the legitimate means through which any research to the committee should be legitimated. But for the committee, critiquing research which is open about its own ethical position is problematic and of course numerous hurdles were put in place to prevent the securing of approval. This in turn, whilst deeply uncomfortable on an individual level, made visible some of the issues that concern ethical review committees which when it came down to it had less to do with ethics than with personal bias, the order of the LREC was made visible through breaching the order of the LREC.

In summary, the thesis, whilst focussing on intensive care and intensive care technologies aims to make explicit the ways in which bureaucratic systems move and

constrain individuals to behave in a certain way. It is about embodiment, the problems of embodiment and the way practices are embodied. It is concerned with spaces, from the invocation of emotion (Bachelard, 1994) to a good or non-existent space (More, 1551) and the spaces in between (Foucault, 1986) it is about real, here and now spaces and the imagined spaces of popular culture (Soja, 1995; Hetherington, 1997). In short it is a tale of desire, a desire to perform a piece of research which has meaning in a way that is true to the theoretical position and beliefs of the researcher. In this latter sense it is a thesis about success and failure, of not compromising principles and the weight of systems to ensure that such a piece of research fails. It is not a story of ethics in intensive care as much as it has become a story of ethics-and-intensive care. As Foucault (2001) has made clear, there are a number of risks that are brought in to play when perspectives differ and these perspectives can become dangerous when they are spoken. The research has taken these risks throughout its course, through its engagement with ethics and they have continued through the course of writing up this ethnography. But for now, it is time to perform last offices on this thesis that plays with tropes, to 'lay out the body' of the research, to once again make those dangers visible.

Chapter Two.

Notes on an Ambiguous Position: declaring theoretical assumptions.

Introduction.

'I wouldn't call myself a 'symbolic interactionist', in part because I'm drawing on a variety of theoretical resources, and in part because I believe that such declarations of allegiance have the disastrous effect of stereotyping and foreclosing debate.'

(Law, 1994, p. 94)

Within the thesis I do not emphasise allegiance to a particular theoretical way of doing ethnographic research. Rather, multiple theoretical viewpoints thread throughout the thesis because they provide a particular means of understanding culture and society in relation to a particular space. As such any theoretical perspectives that are 'called' upon are used, borrowed, sometimes misused and, in more vulgar parlance, bastardised. In part this is indicative of the 'postmodern condition', to partially misuse Lyotard (1986). Theoretical perspectives are not necessarily invoked as a tool of alignment (Latour, 1987; Callon, 1991; Munro, 1999; 2001) but because they provide a particular insight or frame of reference from which to engage with a particular way of analysing the social. For me, as will be demonstrated throughout the research, the issue is about 'the way I see things', which is neither a right or wrong way of seeing, just the way I see and with this comes an alignment with a particular 'way of seeing'. What is being made explicit is that the way I see the space of intensive care and to some extent, ethics, invokes a particular theoretical and practical methodological perspective that has a certain allegiance. As a result of this, any theoretical allegiance (as Law (1994) put it) is contingent, subject to change and alteration; partial. For me it holds (Latour, 1987) and as a consequence is taken to be worthwhile; in Gouldner's (1971) terms I am making explicit the domain assumptions of the researcher. These domain assumptions are presented and made visible as opposed to following a thread of theory that best fits the way I see the world and then hiding it through a particular literary technique. This, I think, has for the most part been accomplished and it ties in with research as praxis (Lather, 1986; Denzin, 2001) and a particular notion of reflexivity (as will be discussed in Chapter Four and Chapter Five). Critically, then, I am making visible how I have constructed a perspective through which intensive care can come to view, but that this perspective is only one among many. The views it allows are partial and the knowledge it generates provisional (Cohen, 1994) and in this sense, the perspectives taken switch

as a means through which different accounts from the research participants can be represented.

The following chapter presents my approach to the field and highlights the theoretical underpinnings and events that have shaped the conduct of research and the structure of the thesis. Traditionally, theses follow a standard format: 'introduction, literature review and methodological chapter' (e.g. Silverman 2000). I am deviating from this structure in that the following chapter focuses largely on theoretically related issues that have informed the way which I have approached the field, together with a brief description of my approach (that is made more explicit within Chapter Four). The theoretical position, from which the research has been approached, conducted and in turn represented stems from a particular engagement with research as praxis. Specifically, the theoretical concerns discussed involve the problem of legitimation and representation (Clifford & Marcus, 1986; Lyotard, 1986; Feurbend, 1993), and some of the means by which social theorists suggest that these problems can be reconciled in the doing of empirical research. Some of the major issues that arise through the empirical chapters refer back to these ideas as consequences of modernity and as such will be made explicit from the outset. This is felt to be of great importance in assuring the integrity of the thesis as a whole, making explicit the position that holds together the thesis as a whole.

While I understood that my research, as a 'native' of the field of study, could not be an 'a-theoretical' or 'a-political' endeavour, my intention was to perform ethically grounded research within a social space characterised by ethical ambiguity, suffering, vulnerability and heightened emotional states. Indeed, my rather undefined feeling that I wanted to help make that ambiguity, suffering and vulnerability visible prompted my desire to do the research in the first instance. The difficulty was *how*? How to make all the complexity that is 'intensive care' visible? How to examine its meanings and consequences for patients, and how to identify its significance, particularly in terms of how it is organised? I held some vague idea of provoking reflection on how (perhaps) intensive care could be reorganised to take account of these meanings and these significances. This was to be achieved through interview accounts from patients and family members, and analysed in relation to the observations of the organisation and practice of intensive care. However, this was the

intention, what actually occurred in practice could not take into account the thoughts and opinions of numerous patients and relied instead upon being in the field observing certain social practices and interviewing a host of intensive care staff. Even so, the volume of ethnographic materials that came out of this demonstrated what a huge task I had endeavoured to undertake in the first instance, as only a small amount of material has eventually been invoked within this thesis. But what this material has provided is a rich account of the ordering work of the organisation.

Critically, I felt that I did not want simply to 'interview' patients and ask how intensive care had been for them. I wanted to be able to connect their accounts of intensive care to what had happened to them while in intensive care and to how intensive care was organised and conducted, specifically and locally. As will be seen later in this chapter, this issue of wanting to be around in intensive care with patients and then connect this to their retrospective understandings and accounts made me run into all sorts of problems. I hit all sorts of questions around issues of representation and legitimation, which, as a result, have become the main concern of the thesis. Ironically, the subject matter that I intended to focus upon, the patients and their families, were viewed from particular spaces of legitimacy and as a result of numerous contributory forces, very few were eventually interviewed and followed up. However, patients in particular remain quite visible in spite of this and are present as sites whereby legitimacy is contested within intensive care.

The opening section of this chapter focuses upon some of the issues associated with modernity, particularly ideas of legitimation and representation. Ideas of praxis will emerge within Chapter Four and will be lightly touched upon here. What will be invoked are some of the consequences of modern organisations, particularly processes of disposal and dispersal and will be discussed in addition to the idea of *différance* (Derrida, 1972). These can be seen as accomplished as an effect of rendering 'other' and within the empirical chapters and discussion these issues will take on increasing significance. Through the research some issues arose that related to bureaucratic systems and to some extent systems of audit (Power, 1999). The effects of seeing the world in a particular way and in turn the way I intended to perform the research made visible such effects of audit and auditability as a particular cultural performance (Munro, 1999) and will be presented within this chapter.

A key feature of this research concerns the means through which materials are invoked, aligned with (Munro, 1996a; Latimer, 2004; 2007) and disregarded at different points. In this regard, the thesis is not unlike actor network theory. However this is not an actor network piece of research; materials, whilst related to in similar terms to that of Callon (1986) and Latour (1987), are dealt with slightly differently. It is not just through a network of materials (human and non-human) for example, that given meanings are produced. This thesis takes the perspective that meanings are constructed *post hoc* (Garfinkel, 1967). The means through which meanings are constructed is within a fabric of relations to others, to cultural materials, cultural artefacts and actively performed in extension to these relations (Strathern, 2004; Latimer, 2004; Munro & Latimer, 2006). The final section of this chapter concerns entering the intensive care unit, in some ways it is a thick description (Geertz, 1973), and its inclusion here could be questioned as a result. However, this short extract is presented in order to introduce the subject matter of the thesis and bind together those theoretical components that have been made visible throughout this section. In this way, the short (re)presentation of entering the field acts as a trope for the major tenets of the thesis which culminate in the discussion. These major themes concern modernity, performance and cultural practices and will be invoked in relation to this research.

Once the theoretical position is examined, a start can be made to examine the cultural scene of the intensive care unit (ICU) as evidenced from historic accounts and those 'lay' accounts found in popular literature (in Chapter Three). The aim is not to force a peremptory literature review, but to gain a foothold of understanding of what the intensive care unit might be, what one accomplishes and how it is thought about and represented. It is posited that only through presenting the cultural scene of the ICU, admittedly as a second or greater hand (re)representation through recourse to different media, can preliminary understandings of the micro-culture of the site be made. Only having demonstrated some preliminary understanding of what the cultural scene might be, can one really start thinking at all about methodology and the practical contingencies of performing the ethnographic research, as these accounts are themselves bound in with the culture of intensive care, albeit on a broader scale. Further, in order for an appropriate critique of the thesis as a whole, and the introductory chapters in particular, it is necessary to understand the *position* from

which the arguments have been formulated. It is recognised that a multiplicity of potential positions are possible, some of which will be outlined in order to frame understandings of how this representation of ethnographic research itself was conducted, whilst paying respect to ethical and epistemological problems wrought from postmodernism, poststructuralism, postcolonialism as well as a desire to perform ethically sound research. This research is largely framed from a unitary perspective of an individual (Cohen, 1994; Rapport, 2003), that of the researcher, the significance lies in what can be shown, particularly with regard social relations in an environment where social relations are characterised as having ceased.

Research is not an ‘a-theoretical’ or ‘a-political’ endeavour (as previously stated), but is deeply entrenched within theory and politics (Friere, 1990; Lather, 1986) through the individual (Cohen, 1994; Rapport, 2003). The setting-up ‘textually’ of the cultural scene in Chapter Three and this theoretical outline being no exception. Ethnographic research is, necessarily, a social act (Benny & Hughes, 1956; Geertz, 1973) performing the social at the same time as analysing the social (Gouldner, 1971). Therefore, to partially compensate for these epistemological tensions, the following chapter aims to tease out those issues that gave rise to an alleged crisis of legitimation and representation, and demonstrate how some of the issues have been circumvented (and within Chapter Four rendered problematic), within the construction of the text, the reading of the social milieu, and the performance of the research itself.

Notes on an ambiguous position.

For Habermas (1993), the idea of modern crops up throughout history, its 5th century Latin root ‘*modernus*’ being used to discriminate the present from the past. More generally modern is taken to signify the enlightenment project, a period whereby science, morality and art became key technologies in order to rationally organise everyday social life (Habermas, 1993). Their role is to utilise individual disciplinary knowledge in order to benefit both the individual and society as a whole, as Auguste Comte reputedly stated ‘to know, is to predict, is to control’ so legitimacy was placed on professional groups to take sole control on their own specialised areas of human life, developing empirical understanding, predict likely ‘outcomes’ from this knowledge and ‘control’ society in aid of a common good. This particular positivist

idea of the constitution of modernity is a particular feature of how intensive care sees itself, as will be made more explicit through the ethnographic chapters. For the moderns of the enlightenment:

‘there is only one possible way to answer a question...’

(Harvey, 1990, p.27),

Through the rational thought of modernity, the one possible answer, the truth will always emerge. Yet this ideal of utilising technology to the benefit of all, that ‘there is only one possible way to answer a question’, denigrates the idea of the possibility of the alternate. It is predicated upon assumptions that are not made explicit, are cultural, and are held to be true. Truth and reality in turn become a cultural consequence, they are practised and in turn become the way the world is witnessed (Senah, 1997; Verran, 2001; Law, 2004) through their continued performance, production and reproduction. This issue will be returned to through the ethnography and will be returned to within the discussion (Chapter None). However, the issue of having one way to answer a question is a cultural accomplishment that holds, as will be made evident through a negotiation of an ethics committee. Throughout the ethnography, the single answer increasingly comes to be seen as resting upon increasingly shaky cultural assumptions and I will demonstrate the partiality of these things that hold on one level, yet fall apart on another.

Things fall apart; the centre cannot hold;
Mere anarchy is loosed upon the world,

From *The Second Coming* by W.B Yeats.

The problems of legitimacy are set around the idea that at one (modern) historical epoch, it was possible to ‘see’ the world from a particular standpoint. This all encompassing meta-narrative (Lyotard, 1986), or way of seeing the world, silences other, perhaps equally valid, worldviews. For Harvey (1990), the import of Yeats’ passage (above) is in how it captures the spirit of the failure of a meta-narrative and the consequences of it. The world is more complex than is possible to be viewed from a single perspective, the meta-narrative can in turn, as Verran (2001) and Law (2004) highlight, be seen as a particular performance of culture. Through giving more credence to a certain worldview, other worldviews are, by implication, suppressed. The unitary worldview is legitimised by the silence of other worldviews, maintaining its dominance through its own domination (Giddens, 1986) and as a consequence being accepted as ‘fact’. Alongside a ‘univocal’ world view a binary opposition

emerges, between the fact and any other understanding. Throughout this thesis these issues are explored in relation to processes of othering and providing accounts of those issues that 'hold' (Latour, 1987) within the culture of intensive care. As Harvey (1990) aligns the sentiments of *The Second Coming* with questions surrounding post-modernity, this chapter aims to examine these issues, to destabilise the centre (Derrida, 1978) without 'falling apart', textually, theoretically or empirically.

As there can only be one answer to a question, so there can only be one way of seeing the world. What will emerge through this ethnography is how the question changes in order to expedite a certain action and the consequences of a given world view. In part as an effect of modernity through a particular way of seeing, the mechanisms of bureaucracy (a tool of organising modernity) have the effect of limiting affect (Bauman, 1994). Notably affect is limited to the interests of the organisation through a commitment to the organisation as a whole and to work colleagues, emphasised through such practices as team building for example. Within intensive care, as will be demonstrated through Chapter Three and Chapter Six, boundaries are set up between 'the team' (intensive care) and the non team. A cultural implication being the manifestation of the 'civilised modern' and the uncivilised 'other' (Bauman, 1989), as demonstrated in postcolonial theory (Said, 1978; Fanon, 1961). The other as non 'us', or non human, once refigured as such, allows actions which would not ordinarily be performed to be performed, such as genocide for example (Bauman, 1989). Modernity, or at least one way of performing modernity, can have disastrous implications; this, in part, can be seen as an effect of othering practices which are bound in with a particular mode of ordering and the limitation of affect (Bauman, 1994). As a consequence of these issues, the theoretical position and the thought that goes into the framing and conduct of the research become crucial if it is to be ethically sound.

Even the philanthropic ideas of modernity, such as the 'humane' care of people with learning difficulties, became a means by which they later became hidden, neglected and enabled a 'legitimate' treatment as 'sub-human' (Ryan & Thomas, 1987). Once rendered other, even with philanthropic intent, a marginal position is set up from which actions not necessarily envisaged from the outset become easier to be conducted. The themes that emerge are not dissimilar to the killing of the disabled and

lame in Nazi Germany. The murder of the disabled, and the mass murder of Jewish people, as Bauman (1989) contends, was made possible by the intolerance, some ascribe to 'civilised' modernity. So, legitimation refers to the dominant voice, that is, the worldview that is considered legitimate and given the voice to define a given situation within its own terms. The legitimate voice in turn becomes the way in which culture is performed. Through this recognition, the unitary turns to a multiplicity of accounts, worldviews, which represent multiple realities and the unitary, in this case 'scientific' (positivist) voice, is recognised as being unable to account for all phenomena (Lyotard, 1986). Modernity can be seen as a particular way of seeing the world and has particular effects, which will be made more explicit through the ethnography.

'...researchers are making use of their common sense knowledge of social structures in order to get the work done in ways required by the format. The complexity of the putatively 'real' social world is 'reduced' in compliance with the requirements of the format itself...'

(Benson & Hughes, 1991, p123)

Although Benson and Hughes (1991) are referring to variable analysis (positivistic methods) in their ethnomethodologically framed 'indexical' (Garfinkel, 1967) critique, the principles remain. The real world, which is perceived through a common sense gaze, is reduced in compliance with certain, in this case, 'social science' format. That which is 'common sense', is experienced through existence, or 'being-in-the-world' (Heidegger, 1962), and is reproduced as 'social science sense'. That is, the world and its complexity has to be reduced to fit with a particular way of seeing the world, or a particular way of doing sociology (or indeed science). For Luhmann (1990) and ethnomethodology in general, the reducing is a technology, or more accurately, the effect of technology is to reduce or simplify, rendering something visible whilst obscuring and concealing the 'other', which in turn is that which escapes or does not fit the technology.

'Against positivism, which halts at phenomena - "There are only *facts*" - I would say: No, facts is precisely what there is not, only interpretations. We cannot establish any fact "in itself": perhaps it is folly to want to do such a thing'

(Nietzsche, 1968, p267(481))

Without a unitary world view though, the world becomes impossibly complex, difficult to tie down and near impossible to reproduce, or represent textually. Within a modernist frame, the world view has a certain means of representing a given reality, as the academic thesis is organised along certain lines (literature review,

methodological chapter and so forth) it is viewed as the legitimate frame of representation, as is the presentation of natural scientific papers through hypothetico-deductive representations. However, if one takes on board that there are multiple world views; the problem lies in representing the world views without prejudicing others. As Atkinson and Coffey (1995) emphasise, the social science text has reflected an ethnocentric bias as much as academic rigor, colouring perceptions of 'other' cultures, which in turn shapes the way the 'other' is witnessed and understood (Said, 1978). When representations of culture are invoked, what is happening is an interpretation of culture, as Nietzsche made visible in the preceding quote, and this is demonstrated within the ethnography (notably Chapter Six) with reference to physiological 'representations'. To again recycle Nietzsche (1968), 'There are no facts only interpretations' and these interpretations when transformed into the factual can have particularly dire consequences. This thesis and those representations of a cultural scene (Chapter Three) are themselves interpretations, of other interpretations, and in the vein of Joyce (cited in Fletcher, 2001), are (re)interpreted as part of this thesis.

The text plays a role in how the world is perceived, and it is through the text that abstract philosophising is made possible. In turn the abstractions made possible through the text in themselves become a cultural performance (Ong, 1988), 'there is nothing beyond [outside] the text' to use Derrida's (1976) frequently cited sentence. However, the world *is* textual, literacy and textuality has made it so; a situation is 'read into'. Discourse, whether textual or verbal is 'read', as are social encounters (Goffman, 1959, 1967), even the (largely) visual 'spectacle' of the media (Debord, 1994, McLuhan & Fiore, 2001) is dependant upon text (the news reader, reading from a script), and makes sense to a 'textual' audience; thus having a profound influence on the way the world is 'constructed', understood and performed (Gebser, 1985; Ong, 1988). Even so, what is to be written is not known until it has been written (Derrida, 2001). The text is temporally static, authorial intentions at the point of writing become 'forgotten', whilst new readings are made of the text beyond 'authorial intention' (Derrida, 1967; Bauman, 1989). Given the Wittgensteinian (1953) notion that there is a direct link between thought and talk, or the signifier and sign of de Saussure (2006) it is not the antagonism between speech and text that becomes the issue (Derrida, 2001). The issue becomes how the text changes the way the world is thought about,

and thereby talked about (Ong, 1988). The point is that if more than lip-service is to be paid to the representation of a 'cultural scene', then at least a rudimentary understanding of the power of text is made increasingly necessary. This needs to be presented before one can discuss those 'devices', or techniques which can (at least) assist in an adequate representation of the cultural scene. Perhaps, even the verisimilitude of 'representational' (or more accurately interpretational) textual devices (Denzin, 1997), can be read as an alternate partial account. That is they become themselves a victim of precisely the same charge of privileging certain voices, albeit unwittingly, as has been levied against unitary sovereignty.

The representation of the research in textual form along social science, or any other, pre-held conventions runs the risk of silencing the 'voice' of the participants. The researcher holds sovereignty over the interpretation of the research on the basis of their academic background and theoretical position. Much as Plato's (1955) imagined philosopher kings held sovereignty over their subjects, the researcher has ultimate sovereignty over the interpretation and representation of what has been observed. The text itself is disembodied, presented within the constraints of the scientific convention omitting the voice of the investigated with its detached striving for objectivity and scientific acceptance (Atkinson & Coffey, 1995; Hopper, 1995). This sequestering of the voice of those who experience the day to day reality of life within a given cultural milieu, and the framing of research within abstract theorising often fails to represent lived reality (Hopper, 1995). Perhaps a more troubling consequence is that the researcher can be guilty of perpetuating and legitimating forms of cultural oppression (Street, 1992; Atkinson & Coffey, 1995). The reflexive 'turn' of collaborative discourse is a means through which contradictions in theories, values and actions can be identified through the voices of those who bear witness to the power relationships which are made visible within everyday social life. Without paying attention to the problem of legitimation and representation, the researcher is then seen to be representing, legitimating and prolonging the power imbalances already present within the cultural scene (Street, 1994).

It could be argued that an empirical 'rape' has been committed in the process of performing research, through eliciting accounts of suffering, of hope, of loss, of the

end of individual human existence as part of an examination of intensive care. This is not to suggest that ethnographers in emotive settings are predatory, on the contrary, recognition is made that within such a context it is not easy to reconcile 'pumping participants for information'. Sensitive research needs to pay respect to the multiplicity of accounts, arguably offering something in return for being involved in research conducted in emotionally charged arenas (Lather, 1986). The sensitivity of the research (it is hoped) is accounted for against a background of colonial ethnography (Skeggs, 2001), a theme that will be developed in Chapter Four.

In making texts or discourse emanating from research more 'open' to analysis in its representation, the text, whilst straining for inclusiveness, amounts to a series of quotations that are so open to a multiplicity of meanings to be meaningless. No attempt is made at theorizing (Hammersley, 1992), which leads to the issue of 'interesting, but so what' (Snow et al., 2003, p.183). From a Geertzian (2000) perspective, the subject matter has become so guarded against causing offence that no analytical sense is made of the experience. In treading the path of literary devices aiming to 'open up' the text to verisimilitude and representations of a given culture, the literary device becomes as 'power-drenched' as that of the position of sovereignty held by the researcher, that which it aims to thwart. We are left in a state of theoretical nihilism, whereby nothing is 'true', unless pains have been made to attest it to the 'rigour' of a literary device, of a literary device which lays claim to veracity through making the text truly represent the opinions of individual social actors.

This nihilistic position renders the world almost a Baudrillardian 'simulacrum', whereby no interpretation is really real, until it is taken to be real (Gane, 1993) and the Kierkegaardian idea of truth being embedded in subjectivity becomes the norm. That is, whatever 'I' take to be true is by implication *the* truth. That which is taken to be 'a truth' is imposed on an illusory universe, making it real, doing away with the ontological insecurity associated with the illusory, or indeed the meaninglessness of the 'universe' (Sartre, 1989). However, this applies equally to theoretical interpretation and perhaps subversion of the research participants view point that everything and nothing is true, a charge that could similarly be levied against critical realism (Bhaskar, 1978; Sayer, 1992), whereby every interpretation retains its veracity so long as the epistemological viewpoint has been made explicit. So why bother

theorising? Have we reached a position that just as ‘everything the artist spits is art’, ‘everything the social scientist spits is unequivocal social science’, saturated in its own veracity? Why should we perform research when any conclusion, no matter how spurious is equally valid? But despite these almost nihilistic tendencies, this is getting close to the crux of the ‘problem’, as Rorty (1979) asserts:

‘truth is always partial, certainty unlikely, facts factitious and the best that one can get along with is some intelligent vindication of ‘asserted reliability’

(In Inglis, 2001, p.134)

We live in a ‘sea of stories’ (Bruner, 1996), of partiality (Rorty, 1979), theory reduces and text suppresses and attempts to reduce the impact of issues arising out of the problems of legitimation and representation, there can no longer be an argument but an acceptance that all accounts are legitimate. An impasse is reached, a terminal aporia whereby a certain position cannot be treated as superior to another but all positions are not at the same time knowable and presentable within a coherent text. In addition, as critical theorists attempt to destroy the ‘grand theory’, ‘accidental’ grand theory replaces it (Skinner, 1990). So, in coming to terms with a position from which to understand and interpret research, taking into account multiple voices, some voices will be lost, the aim is to ‘adequately’ represent a cultural scene, and the voices of those within it. Whilst this may seem an epistemological ‘cop-out’, there are further issues at stake. The intention, so far being to present certain issues which may enable (or perhaps disable) the analysis, performance, engagement with and representation of social science research in general, and this ethnography of intensive care in particular. Critically though, these positions are read as cultural fact, the main aim of this thesis is to look at those ideas that hold (Latour, 1987; 1991), culturally and particularly, the ways in which they are performed. Culture is produced, reproduced and displayed and through some of the performances within a particular area of the hospital, the intention is to make visible ontology as a particular cultural performance and some of its effects.

This brings us somewhere near to the position of Latour’s (1987) fourth dictum of Janus (p.12); that which is true does not hold because its true, it is true because it holds. For Kierkegaard (1992), there can be no meta-narrative as that which is subjectively held is individually true, there are multiple interpretations, but no ‘facts’ (Nietzsche, 1968), truth is always partial (Rorty, 1979). It is within this context that

this research can be viewed, it is simply a series of accounts of intensive care, if theory is generated from it, that theory can only ever be a partial explanation, if that. The focus is on the collation of accounts, and the accomplishments that such accounts produce. Even so, consideration needs to be given to how the accounts are represented textually (and digitally), and how they are legitimised within their own context, the context of individual human experience and the context of culture. Significantly, what is being attempted is a position in which research participants are respected as persons. However, as Feyerabend (1993) made explicit the method of doing research is not just a given theory but is in part reproduced within 'distinct constellations of activity' (Lynch, 1991). Through this ethnography, the conduct (Latimer, 2000) of 'doing being social' (Sacks, 1984) is taken as the means through which social life is consumed, produced and reproduced (Munro, 1997; 1999). As the self is understood through a fabric of relations (Lyotard, 1986), culture and social life can be seen as being partly reproduced through extension to cultural materials (Strathern, 2004). That is social life is understood through extension to its relations, to materiality, to tropes, to metaphor to otherness, as opposed to being located within a certain specificity of say an individual position in stasis. It is through such relations of extension, to materiality, and cultural artefacts, that a given cultural order is 'bought into', produced and reproduced and embodied; this remains a point of reference throughout the thesis.

Theoretically, what has been discussed thus far states a position of the dangers of not paying adequate attention to the challenges of postmodernism, poststructuralism, postcolonialism and the consequences of performing ethnographic research. The practical contingencies of the research itself will be discussed later (Chapter Four), as it is felt to be important to delineate the 'life' of intensive care as represented in textual form. So, the position alluded to so far generates a position from which the thesis may be judged, but it is also, by implication, reduced to this position. But then, so what (Snow et al., 2003), nothing new has been discussed so far, old paths have simply been re-trod, no 'new' position has been reached from which understandings have or can be made, the position itself is suffused with ambiguity, a context is required, without it this 'abstraction' is in danger of spiralling pointlessly out of control.

However, these discussions are not new and have been encapsulated previously as arguments concerning relativism (Melchert, 1994). As far as this thesis is concerned it developed from a means of producing research which aimed to thwart some of the perceived threats to the critically ill and their families, which was a motivation for doing the research in a particular way. More closely aligned to Lather (1986; 2001) and Denzin (1997), the intention was to offer something back to the participants of the research given my clinical training within intensive care as part of the ethnographic work. This arose from a particular point of perception, beyond that of the ethnographer as a 'fly on the wall' and making explicit, or even more crudely celebrating the impact that the researcher has on the field that is being researched. The distinctions of inside, outside, of truth and fiction begin to untangle once the recognition is made that ethnography is the writing of others (Van Loon, 2001). Ethnography can be seen as autobiography (Clifford & Marcus, 1986), and as has been made explicit elsewhere (Van Loon, 2001; Stacey, 1997) autobiographical accounts can be seen as ethnography. Whilst the intention was never to perform an auto-ethnography, this was in part produced and is theoretically consistent with the research itself. In part an artificial distinction between auto-ethnography and ethnography has been produced here, which exists as a means of separating quite different aspects of the research, even if represented through one author and treated as part of a thesis as a whole. However, whilst remaining consistent with the theoretical position, the differentiation between the auto-ethnographic Chapter Five and the ethnographic empirical Chapters will remain so as to prevent confusion, but in the recognition that the authorial voice of the ethnography remains a representational concern.

The theoretical position of this thesis owes a debt to science and technology studies (Feyerabend, 1993; Hacking, 2000; Latour, 1987; Calon, 1991) as a position from which it has arisen and from which many of these debates have occurred previously. In that sense, intensive care is seen as a cultural performance (Munro, 1999), with its own particular cultural accomplishments (Garfinkel, 1967). It is within this frame of reference of science and technology as a particular performance of culture that has in part led to a re-thinking of this epistemological position and its relation to the ontological. In this sense it comes from a particular tradition that has developed around science and technology studies and in particular, this research teases out issues

of technology as a cultural effect (as an organising and limiting principle) as opposed to the constructions of, for example, laboratory life. However, what this ethnography takes as a point of reference is in the approach to method and the ties between the epistemological and the ontological, as understanding being constituted through a fabric of relations (Lyotard, 1986; Feyerabend, 1993; Strathern, 2004)

Once multiple voices have been accounted for, once the recognition is made that there are indeed a multiplicity of, equally valid, accounts, another problem comes to the fore. The issue turns to how some views marginalise others, how some voices, some ideas are made peripheral. The ‘move’ (Lyotard, 1986; Latour, 1987; Flax, 1989) that is made recognises that within the social, some accounts dominate others. That which is taken as fact (truth) holds because it holds (Latour, 1987), the individual accounts or subjectively held truths (Kierkegaard, 1992), whilst partial (Rorty, 1979), are swallowed up through the discourse that holds. This ‘play of discourse’ itself comes under scrutiny within questions of how it marginalises others, and what it accomplishes in so doing. The self ‘exists in a fabric of relations’ (Lyotard, 1986, p.15), discursive moves are played out, hierarchy and order are accomplished within the social. The question of sociality and its relations, is not static but suffused with moves and countermoves (Lyotard, 1986), ‘choices’ are made. It is in the relation to the discourse embedded within these moves and counter moves that an analysis of their formation, practice and accomplishment will be made. It is from this point that intensive care as a socio-cultural space will be examined and from which the performance of culture can be contextualised.

On surmising an approach.

The ambiguities of the epistemological position of this thesis arose out of critiques of legitimation and representation, and this thesis in no way solves the problems associated with them. Legitimacy is examined in relation to certain perspectives that hold (Latour, 1987), such as a historical origin of intensive care (Chapter Three) or an alignment to a certain ethical principle to ensure the discharge of a ‘troublesome’ patient (Chapter Eight). The research has been judged as falling short of being legitimate by an ethical review committee and the accounts of their reasoning and my reactions to them are referred to in Chapter Five, but remain a stable feature of

analysis of the thesis as a whole. In part, the ethical committee demonstrate what they take to be legitimate through their dispersal (Foucault, 1972) of the illegitimate, that which does not fit their criteria for legitimacy. In part the thesis deals with how certain aspects of social life are taken as legitimate or otherwise and is read in relation to some of the consequences of such judgements. Once rendered other, that which is not legitimated is dispersed. It is not necessarily disposed of, as it reappears (for the most part) as this research was dispersed through numerous panels of an ethics committee before finally being held as legitimate. In Derrida's (1972) terms it was different and as such was deferred, only to re-emerge once the application had been re-written within the terms of the ethics committee(s). The term used through the thesis to describe *différance* (Derrida, 1972) and dispersal (Foucault, 1972) is, for the most part, disposal (Munro, 2001), not because something is necessarily always disposed of, but because an attempt is made to dispose of a given idea, an idea that is not legitimate. For the ethics committee or intensive care that which is legitimate needs to follow a certain format, and through *différance* the attempt is made to deny or *refuse*, to rubbish or *refuse* (Douglas, 1966; Munro, 2001) an action has been undertaken from which any further negotiation (at least for a time) is unnecessary as the situation has been disposed of irrespective of the possibility of return.

'...most behaviour is closely embedded in networks of interpersonal relations...'

(Granovetter, 1985, p. 504)

Rather than seeking a 'truth' or making certain claims predicated upon the factual, this thesis traces the relations of accomplishments (Garfinkel, 1967). It is not facts, but interpretations (Nietzsche, 1968) and accomplishments of the taken for granted social order that is made visible. Whereas Lyotard (1986) emphasised the location of selfhood within a 'fabric of relations', akin to symbolic interactionism (Goffman, 1959, 1967; Blumer 1986), this thesis follows Strathern, (2004), Latimer (1999; 2004) and Munro (1996) in examining how the accomplishments of social life are made visible to such fabrics through relations of extension, not necessarily questions concerning selfhood as Lyotard (1986) has it. Whilst on the one hand individual social actors are embedded (in Granovetter's (1985) terms²) within a certain cultural

² The idea of embeddedness reappears as a trope in Chapter Six in relation to Collins' (1996) critique of Artificial Intelligence – embedded or embodied? Within the present context, Granovetter is focussing on economic action, the trope of networks in relation to economics gains prominence in relation to Actor Network Theory's use of economic theory as a means through which materials are given cause for social analysis, particular by Latour (1988) and Callon (1991).

order, they are in turn producing and reproducing such a cultural order and it is through extension to cultural artefacts such as ideas, rules, histories, technologies and their invocation that the tacit and taken for granted aspects of social life are made visible. That is, a given cultural order is made visible, not of itself, but through its invocation (Bhabha, 1994; which is presented in Chapter Three and Seven), its disposal (Derrida, 1972; Foucault, 1972; Munro, 2001; which is presented in Chapters Six and Seven), its alignment (Fujimara, 1987; Latour, 1987; Callon, 1991; Munro, 1996, which features throughout the thesis) and as such is understood through such relations of extension (Strathern, 2004; Latimer, 1999; 2004; Latimer & Munro, 2007; Munro, 1996) to cultural artefacts. The significance of embeddedness (as opposed to engrossment (Latimer & Munro, 2007)) becomes more clear within Chapter Six, as it is demonstrated that only once embedded within a cultural order, can the body be read and activities performed around it that are in part legitimated through such embeddedness.

'Ethics is a social actor frequently enrolled to justify auditing practices, yet as frequently seen as betrayed by or in resistance to them'

(Strathern, 2000a, p.5)

It is through such relations that organisational practices, such as audit, can be seen as a cultural performance (Munro, 1999). In many respects this thesis takes Munro's perspective (among others) as a means through which the culture of intensive care and of ethics can be made visible. As Strathern (2000a) highlights in the preceding quote, ethics can be invoked in order to make available certain cultural performances, such as audit, once invoked and aligned with, performances of disposal can be seen as legitimate. It will be suggested that the strength of the invocation and alignment that legitimates the disposal rests in part in how it 'holds' and 'stops' (Latour, 1987), any alternate mode of inquiry. The invocation, alignment and disposal are part of an embedded cultural performance. This is not to say that they represent the only possible interpretation or action, but the one that discursively holds (because it holds (Latour, 1987)). This means of producing and reproducing culture is a part of how mundane understandings hold, yet such relations are not fixed, but as will be demonstrated are made and remade, the connections are partial (Strathern, 2004). Whether culture is presented as an anthropologist playing a game of dominoes in the pub (Rapport, 1999), or an individual embroiled in a scam (Rapport, 1997), there is a certain cultural scene that the anthropologist is immersed in. From the perspective of

an individual social actor it can be difficult to see the social world in alternate ways. However, a theme woven through the thesis concerns such cultural performances, particularly the issue surrounding its impact on the individual (a researcher or an intensive care patient, for example). The power of a given cultural order can be made explicit through breaching (Garfinkel, 1967) such an order, and the power of the individual to resist (Rapport, 1997; 2003) a particular way of seeing, such as the place of the patient or the role of the ethnographer, is made visible through the techniques and technologies used to ensure that the individual fits the cultural program (Latour, 1991). In turn these techniques and technologies of conformity provide a telling insight into how culture is produced and reproduced in relation to a given cultural material, such as ethics or safety. This is a key issue, of shifting perspectives to see what it tells of culture and of the place of the individual in a performative culture of accountability.

In part this research stakes its own claim to legitimacy within the text, presented as a representation of a given cultural scene. However, it more closely resembles an interpretation and one of many possible interpretations, yet the way in which the text is written, and to a large extent that which makes the final cut into the thesis is bound in with that which is legitimate to a broader argument. The intention is to look at the culture of intensive care in relation to its accomplishments and broader readings of intensive care. A fabric of relations between physical materials, discursive materials, performances and ethnographic moments have been placed together in order to provide a feel for the space as part of this broader of the thesis. In part this is where this thesis differs from the dealing with materials of Latour (1987, 1991), as well as the treatment of the embodied subject (Collins & Kusch, 1998), although the issue of holding and materiality remains strong throughout. The textual representation of intensive care becomes more akin to an ethnographic interpretation of intensive care through which certain actions and their consequences are made visible. In turn, other aspects of social life are concealed through certain cultural practices. This thesis alternates between those aspects of intensive care that are made visible and those that are concealed, neither of which are fixed and static but are mobilised at different points in order to emphasise (and expedite) quite different actions. The major point of departure of this thesis from any ethnography of intensive care that has gone before is that those aspects which are concealed, the mundane everyday practices, are

magnified at points (what Strathern (2004) refers to as amplitude) in order to demonstrate the ordering work of modernity in a specific cultural site. A specific space that I will briefly introduce as a space that I both had great difficulty in accessing (in relation to the Local Research Ethics Committee), and great ease in accessing (in part as member), will be turned to in the next section of this chapter.

Obey the Signs.

Signs move folk, they order what should be done, they are littered almost everywhere. From the moment I enter the hospital (and even before), signs outline where I should go, how I get there and dictate how folk behave in different areas (floor plans can be found in Appendix Four). On alighting from the lift that helpfully reminds me which floor I am on, a set of signs warn me not to enter the operating theatre unless I am a member of hospital staff and tell me the way to the 'Intensive Therapy Unit'. I stand in the centre of a crossroad of green linoleum, directly outside the entrance to the operating theatre. Four lifts are either side of me, the lift to my left states that it is for operating theatre use only, the entrance to which is to my rear. A few steps forward, a sign represents the threshold to the 'Intensive Therapy Unit', further emphasised by a change in linoleum colour. A security camera hangs from the ceiling; a trail of plain grained grey linoleum spreads to my left and right to other hospital units that share the same floor. Ahead lies the intensive care corridor, decked out in pale blue linoleum, seaside scenes ingrained within small cream circles that mark the path onward past a hastily written notice that 'the critical care labs have moved'. Walking down the corridor entrance to the intensive care reception desk (or Intensive Therapy Unit as the sign informs me) it appears that little sunlight reaches here. Various offices line the thoroughfare, artificial light being the mainstay of luminance, with the occasional wedge of light coming in from open doors.

A wedged open doorway reminds me that smoking is not permitted and lies between offices, of nurses, managers and doctors, it is a lone open door on the corridor, lying adjacent to a 'relatives washroom and toilet'. Waiting people sit on sofas, talking, watching the television, a jocular voice nervously twitches over the tension of the room, the coke machine clangs as its load is deposited. The room is segregated from the corridor by its carpet, a means of differentiating the clinical from this 'holding

pen', the cartoon impregnated linoleum stops at the threshold of this space; the space is a place where waiting happens. Its captive audience are directed to notices delineating how to conduct oneself within the confines of the intensive care unit; wash your hands, respect patients' rest and so on, a file is spread open over the coffee table and tells anyone who's interested details of what an intensive care unit (ICU) is and what happens to 'loved ones' whilst in this place. This is a space where people wait, the comforting look of the sofas belying the fact that this could be a doctors' surgery or airport lounge (Auge, 1995), the corridors artificial light vying for attention from the sunlight that seeps in through the window of this, the 'relatives room'.

Having walked toward the ICU reception, another lift lobby is faced; signs tell you that the use of the lift is for staff only. Pictures of staff and children line the walls, a rogue's gallery of people you may encounter within the Paediatric Intensive Care Unit (PICU). Pictures of children, sick and well of various ages represent the survivors of PICU, some bearing slogans such as 'Made in England, Saved in Wales' assembled into a collage of faces, newspaper clippings of 'saved children', thank you posters by or on behalf of children. Opposite the lift a door enters into the male staff lavatory where another hastily written sign has been placed:

'The toilet is broken AGAIN!'

A battered blue box sits against the wall, whilst ahead sits the reception proper, underneath the desktop is a sign reading PICU with a picture of a dolphin underneath. The receptionists chat to themselves as I turn to the doorway separating the corridor world from the world of the ICU proper. The children's intensive care unit is on the left, whilst the 'critical care unit' is the right turn. As you reach the sign littered doors, you are reminded to 'wash your hands' on entry to the unit and when leaving, you must 'speak to a nurse before entry' and recognise that 'ICU patients need rest'. The signs draw you into a certain way of behaving, of not being noisy, of washing hands, of speaking to the nurse of needing permission to enter and ringing the bell to speak to the nurse. You are reminded that the old ways of behaving, the way of behaving in the public space, no longer apply. This place is different, it is a place where serious stuff happens, woe betides those who enter without obeying the signs.

I, however, disobeyed the sign. The first day of fieldwork, I neglected to take my identification tag with me yet the receptionists were quite happy for me to walk into the intensive care unit. I entered intensive care, walked from one side, the 'B' side to the 'A' side to find the nurse in charge in the office, there was no nurse in charge to be found, so I walked back out the way I came. However, I had not banked upon the nurse, a member of 'agency staff' that are called in to help due to staff shortages for whatever reason, calling me to account:

Nurse: Excuse me

P: Yes

Nurse: Who are you?

P: I'm Paul White

Nurse: I've just seen you walk in

P: Yes, that's right

Nurse: Well what do you think you're doing here?

P: Mmm, I wanted to speak to the nurse in charge, eh. I'm doing research here, eh; I used to work here...

Nurse: I've never seen you before, do you have any I.D.

P: No, actually I've left it at home, but that nurse over there, Shirley, on the telephone, the staff nurse, she knows who I am.

She walked over to the staff nurse and verified my claim; however, from this encounter, I had got an insight into how difficult and challenging it can be to enter an intensive care unit. Rather than stand my ground, claiming the legitimacy of my presence, of challenging the challenger, I retreated. Obtrusiveness (Harrington, 2002) on day one did not appear to be a fruitful strategy, so I left the intensive care unit. Perhaps I should have obeyed the signs, but then which sign? How can I really tell where I am when confronted with conflicting signs, 'Intensive Therapy Unit', 'Intensive Care Unit', 'Paediatric Intensive Care Unit', 'Critical Care Unit', 'Critical Care Labs'. What sort of a place is being entered when the signs don't agree with each other, there is an adult ICU and a children's ICU, the other terms refer to policy changes over the years such as 'critical care' (DoH, 2000), the only constant being that these are 'units', serious units where hand washing and permission is required.

Whilst this may have been my first field encounter, it was not my first encounter with the ICU, having worked there for a number of years as a staff nurse. It did demonstrate that my time out of practice had made me, to some extent, an outsider to the environment. Walking in a couple of days later (identification to hand) no such challenges faced me, comments were directed more to the fact that student life must agree with me, on account of developing facial hair. Outside the doors to the ICU, the

cleaner chats to a family member, the reception lies in between the ICU and the paediatric ICU, opposite which lies an office for nurses and junior doctors, separated by wedged open double swung doors from a portable x-ray machine and some kind of fridge that can be found on the other side of the doors. Having negotiated access to the intensive care unit (on the second attempt), a strong odour of faecal matter came over me as I pushed the well signed swing doors open, something that I was not prepared for and that I was no longer used to. Shoals of medical staff floated from the foot of beds, systematically reviewing each patient on this, the 'B side' of the ICU. Swing doored cubicles mark an entrance to the open planned ICU, posters made by ICU staff inform one of how to pass a naso-gastric tube and the nature of neurosurgical pathology, fridges and filing cabinets rest against the right side of the wall, some bookshelves with old medical textbooks and policy folders rest above a sink. A sea of beds, spread out, and although open plan there is a definite way to walk through, avoid the beds, avoid the machines, avoid the hustle and bustle and get through the place as quick as you can. A radiographer with a portable X Ray machine juggernauts past me like a road rager, I dodge into a sluice room to avoid what I thought may be certain death, or at least a painful toe. This was my grand entrance to the intensive care unit as an ethnographer, a space that I felt I should quickly retreat from.

Analysing the Field.

Within this chapter I have made visible the domain assumptions (Gouldner, 1971) that I hold regarding this research and ethnographic research more generally. This is of significance in presenting research, particularly when attempting to circumvent the problems of representation. Representation is taken to refer to the way in which the research is reproduced textually and the means through which the text can conceal, and by implication holds complete control over the representation of a cultural site. It is also taken to refer to the way in which theoretical assumptions which underlie the research are concealed. This concealing of a theoretical position is taken to have certain ethical implications, particularly as the way a culture is represented is tied in with a particular way of seeing. This in turn has broader ethical implications of perpetuating forms of cultural oppression (Said, 1978; Street, 1992; Atkinson &

Coffey, 1995). Concealing a theoretical position obscures the research, as it rests upon such hidden assumptions.

Luhmann (1990) and Derrida (1976) for example, make explicit that text can have multiple meanings. Through presenting a theoretical position, these textual assumptions can be made visible in part through making visible a certain theoretical position. Literary devices, such as those suggested by Denzin (1997) are important in ensuring that the representation of a cultural scene is true to those who inhabit that culture, what he refers to as verisimilitude. But it is argued, of equal importance is the theoretical position of the research as similar terms have quite different meanings, depending on how and when they are invoked and according to a certain theoretical position. Through making this visible the aim is to ensure that the research is internally consistent, to ensure that through ethics as cultural and theoretical practice, the research does not marginalise other discourses and recognises the partiality of its own. This is achieved through this research's position *qua* ontology and epistemology and is argued ensures the research is ethically sound as a particular cultural endeavour. As a consequence of these issues, the layout of the thesis has altered from the conventional, explaining why the theoretical component is placed at the beginning of the thesis.

Alongside this issue of representation, issues surrounding legitimation have been discussed and tied in with notions of modernity. From Kierkegaard and Nietzsche, issues of subjectivity, of interpretations and their relations to 'truth', or 'fact' have been presented. Whilst aligned to the ideas of Latour (1987, 1991), these issues have been presented as a means through which legitimacy is enacted and taken to hold. This is a key feature of this ethnographic research, the tracing of the means through which legitimacy is produced and mobilised as a particular mode of expediting action or the settling of disagreements. The significance of the theoretical position is through the way in which the thesis aims to make visible legitimation as a particular cultural performance. Legitimacy is taken as a means through which culture can be produced and reproduced and is related to a specific cultural site of intensive care, yet has wider cultural relevance. The research itself was not perceived as legitimate from the perspective of the ethics committee, numerous changes were made to the way the text was presented in order to fit in with the requirements of the organisation, yet the

underlying research was not changed. This suggests that it is in the way the research is represented, not the content and through the content the research as practice, which is significant in ensuring legitimacy within the framework of the Local Research Ethics Committee. In short, the research is concerned with the production and reproduction of legitimacy and the implications of those not deemed to be legitimate within intensive care.

The implication of holding something as legitimate is that something is cast as illegitimate. Within modernity, as Harvey (1990) highlighted, there can only be one way to answer a question, in turn only one perspective can be seen as legitimate. As a consequence that which is not deemed legitimate can be rendered other. As Luhmann (1990) put it organising technologies through reducing difference produce difference. That which does not fit the program (Latour, 1991) of a given technology requires an increasing force of technology in order to produce a required (legitimate) outcome. It is argued that beyond a certain point, that which is not held despite the efforts of technology (be that organisational, cultural or otherwise) is rendered other as will be demonstrated through this thesis. Once something (person or idea for example) is rendered other, or not legitimate, it in turn becomes legitimate to be disposed of. However, the disposed is not truly disposed of, it is incomplete or partial. For Foucault (1972) this is discussed in relation to dispersion (to push away) and for Derrida (1984) this is seen as difference and deferral, *différance* (as pushing away that which is different). These ideas thread through the thesis and in relation to intensive care, the practices can be seen as an effacement, whereby the body is metaphorically othered and physically silenced. This effacement is legitimated through certain cultural and medical practices and is slightly different to difference and dispersal as will be made clear through the ethnography.

The final section of this chapter aimed to present another issue related to gaining access to the field, as mentioned previously this was on two levels, that of the bureaucratic system to perform the research and on this ethnographic level, physically entering the site. It has been discussed within this chapter that the self exists within a fabric of relations (Lyotard, 1986); however, it is further argued through this thesis that materials move persons (Latour, 1991) through relations of extension to cultural materials (Strathern, 2004). As I negotiated a once familiar space, the signs and staff

moved me in a particular way, not only in the direction I walked, but led me to consider the space as having legitimate points of access and entry that are policed by the staff. In part this ethnographic account aimed to highlight the place of intensive care and through doing gave an idea of the space.

In part this demonstrates the idea of membership to a certain group, of calling to account and in Goffman's (1967) terms of saving face and in turn, me leaving intensive care. It is an ethnographic account that has a beginning, middle and end, yet it refers to the power of specific materials that constrain me to act in a certain way and feel that I should leave once the rules had appeared to be broken, the signs ignored. The materials such as the signs (which will reappear in Chapter Six in relation to the Derridean idea of the supplement), the doors, the colours whilst in some ways confusing are emphasised through the actions of the intensive care staff to ensure that my actions are in line with that of the space and when they are seen as a non-legitimate access, othered and disposed of. Through these cultural performances and some of the assumptions an idea of a given space is made visible. Some aspects of intensive care are held on broader historical and popular cultural levels, which in part constitute the space of intensive care. Through this ethnography, the relations to materials and discourses are reproduced and interpreted in order to (re)present intensive care as a particular critical cultural site.

Chapter Three.

Setting the Scene: formulating ideas of intensive care.

Introduction.

The previous chapter detailed a theoretical position from which this thesis is based in particular relation to legitimation and representation. This chapter focuses on some of the representations (or interpretations) of intensive care in relation to its history and the way it is portrayed within the popular media. Within the previous chapter a short ethnographic section was included which gave a feel for the particular cultural space of intensive care as well as a trope to access and the legitimation of access. Similarly this chapter closes with an account of the development of the intensive care unit presented through the research. The aim is to bind the historical and cultural interpretations together and provide a context from which the methods section can be understood.

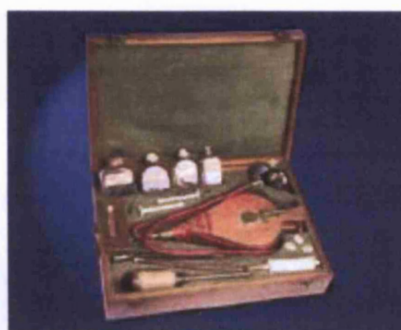
The following chapter is composed of four main sections that aim to provide a background, or context, from which intensive care can be read as a specific cultural site. In section one, a short reading of how intensive care is produced historically is presented. This introduces the way in which (for the most part) nursing and medical writers have contributed to understandings of how intensive care has been shaped. These histories, it could be argued, are set out as part of the development of a professional identity, often being found in the opening chapters of intensive care medicine and intensive care nursing textbooks. For the most part they focus on one particular historical event as marking the advent of intensive care as it has become known within the contemporary hospital. Readings of the development of the specific disciplines within medicine, may tell a slightly different story to the origin of intensive care which may not necessarily rest neatly within the standard intensive care definition within the professional textbook. It is these issues, whether intensive care is viewed as a specific space, a means of segregating the most 'sick' of the hospital population, a specific form of medical technology, or a mode of organisation that in part dictates the definition of intensive care. These readings differ from a reading of intensive care's origin at a particular time and place in history. Through getting a

foothold into the histories of intensive care, a start can be made at eliciting what intensive care might be, from which a background understanding to the ethnography can be made. Perhaps through these differential historical accounts some understanding of how intensive care legitimates some of its actions with regard to other spaces and professional groups within the hospital can be made. This ties in with the coming ethnographic chapters (notably Chapter Six and Seven).

The third section of this chapter explores some issues concerning the development of intensive care through accounts from the field site. This section draws upon the histories presented in the previous two sections, presenting a local and specific history of the development of a particular intensive care unit. The issues raised as part of this development of the field site in part rests upon the previous readings of the developments and origins of intensive care as a specific hospital space. The final section of this chapter aims to briefly highlight some popular accounts of what constitutes intensive care. In brief this comprises of a background to how intensive care is produced within the media, through newspapers, popular literature and television. Through the reproduction of intensive care through such popular discourses an insight into how intensive care is culturally produced can be made. There are quite specific discourses surrounding intensive care that are frequently invoked in relation to non-healthcare related issues, but have as their point of origin a point of seriousness, near death. Those who inhabit intensive care, the staff, the patients, the visitors, are a part of a broader culture which has influences from the popular media, as well as intensive care, be that a workplace, a period of hospitalisation or visiting a friend, a lover or a relative. In this sense intensive care is understood as being produced (and reproduced) as a particular cultural artefact.

A background of intensive care.

The intensive care unit holds a close relationship with technology, particularly that of mechanical ventilation. As mechanical ventilation is one of the main supportive therapies provided by intensive care, this is seen to be its *raison d'être* (Kesiocoglu, 2000). The development of mechanical ventilation is largely held to have come about to suit quite different medical issues, namely the development of cardiac surgery in South Africa, whereby patients required artificial ventilation for a period post-



Picture 3.1 Bellows used for Mechanical Ventilation

operatively (Sykes & Young, 1999) and a particularly ubiquitous citation is from Copenhagen where early forays into artificial ventilation were made during the polio epidemic (Lassen, 1953; Sykes & Young, 1999; Kesecioglu, 2000). Earlier, perhaps abortive, attempts had been made in mechanically ventilating the victims of near drowning through the use of bellows (see Picture 3.1). These bellows were inserted into the lung itself through a surgically created opening through the thorax (thoracotomy) in eighteenth century Britain. The early attempts by the Royal Humane Society to resuscitate victims of near drowning through a method of mechanically ventilating the lungs resulted in death on withdrawal of the bellows (Sykes & Young, 1999). Effectively, the victim had been given a pneumothorax, that is, the lung cannot expand, much like inflating a balloon with a large hole in it. These techniques had been developed from Andreas Vesalius experiments on pigs, which were published in 1543 (Gedeon, 2006). However, for the most part these earlier attempts at providing mechanical ventilation were forgotten about, with arguably less 'brutal' techniques being developed about 250 years later. However, this does demonstrate a part of the history of positive pressure ventilation common within anaesthesia and intensive care as opposed to negative pressure ventilation such as the Iron Lung (see Picture 3.2). What is significant here is that the development of these techniques was not associated with intensive care and perhaps the techniques of mechanical ventilation had a closer affinity with anaesthesia. If it is taken that intensive care takes a point of origin from the development of mechanical ventilation, than the tracings of such technology appear long before the twentieth century.

So, mechanical ventilation itself, in its different forms, has a long history. Although mouth-to-mouth ventilation has a longer history that can be traced to ancient Greece it



Picture 3.2 Iron Lung

is not considered here as its affinities are tied in with resuscitation specifically. Whilst the remit of intensive care revolves around resuscitation in numerous guises it is not specific to and characteristic of readings of intensive care in particular, so will be omitted. The rise of mechanical ventilation itself does not necessarily give rise to the intensive care units. Mechanical ventilation is a feature of intensive care, as is demonstrated throughout this thesis. In many ways mechanical ventilation symbolises the significance of intensive care through the provision of breaths to bodies, the stuff of life. The particular technological development of ventilatory technology, whilst a significant part of the story of the development of intensive care, is not necessarily the point of origin of intensive care as it is known and understood today. Perhaps then, if it is not the development of ventilatory technology, then intensive care is a specific space, as Zussman puts it:

'...Intensive care is not a technology. It is a place. But it is a place in which technology is applied daily to the most intractable of medical problems...'

(Zussman, 1994, p.19).

The significance of intensive care for Zussman is it is a particular place and that place is associated with the technologies that furnish it. It is hard to argue against the idea of intensive care being a place, the fact that the whole of this thesis is about a particular space is testament to it. However, the significance of the space is that it is distinct and separate from other areas of hospital life being characterised by the technologies in use, namely that of mechanical ventilation. It has a higher concentration of health care and support staff than many other areas of the hospital. At the start of this fieldwork, the intensive care unit had its own biochemistry lab and dedicated porters. However these were lost due to developments in laboratory technology, which meant the

intensive care staff could perform biochemical analysis of blood specimens for themselves, and the porters were lost to a general pool for financial reasons. Nevertheless it was a distinct place where resources, such as the staff and the technologies, were located. As will be demonstrated in Chapters Seven, Eight and Nine, the technologies themselves are used elsewhere in the hospital. For example mechanical ventilation is also used within the operating theatre, but what makes these technologies distinct is the way that they are mobilised and in turn the way they shape the way intensive care is practiced. The idea of a distinct place is one that is a particular feature of the history of intensive care and is often located within a particular point in time.

‘...Intensive care usually dates its origins from the polio epidemics of the 1950s...’.
(Bion, 1999, p.3).

The polio epidemic of the 1952 is ubiquitously cited as the origin of what we take to be intensive care, as Bion, a prominent UK intensivist states. It is the site at which, with few exceptions, intensive care is historically located, at least in the UK. It can be seen as not just a place, but a concentration of resources, of technologies in which the bodies of the sick can be treated. Significantly, tracing the origin of intensive care to this point has an impact upon how intensive care is understood in the present. For the UK Intensive Care Society (which prides itself on being the oldest intensive care society in the world), the intensive care unit provides more intensive observation and treatment than is generally available through the rest of the hospital for patients that have a potentially recoverable disease (Spiby, 1989). The polio epidemic is a key example of a potentially recoverable disease, whereby a failing or temporarily failed organ system is supported until the body recovers, a point which will re-emerge in relation to an intensive care patient, Ron, in Chapter Seven and becomes problematic in relation to Dottie in Chapter Eight. To some extent this historical location of intensive care and the definition of it which ties in so neatly with this definition specifically constitutes the culture of intensive care. As such, locating intensive care at this point has the advantage of being allied to contemporary definitions of what intensive care is and what it purports to do. The polio epidemic is durable (Latour, 1991) as a point of historical origin and is tied in with the ethos of what intensive care stands for. However, other points of origin of intensive care could similarly be traced,

at least when ideas of a concentration of the sickest of the hospital population within a specific space is brought into play.



Picture 3.3 Iron lungs arranged within a gymnasium.

To concentrate the sickest of a hospital population within a given space is a phenomenon described from the mid nineteenth century. It has often been argued that intensive *nursing* care, as a development of pooled resources was first utilised in the Crimean war by Florence Nightingale (1997) whereby the ‘sickest’ patients were segregated from the rest of the hospital population and attended to by dedicated nursing staff (Kesecioglu, 2000; Seymour, 2000). Louisa May Alcott (1863) described the use of triage (placing patients according to severity of illness), in the treatment of injured soldiers during the American Civil War, which again suggests that the place of intensive care may have an older lineage. Health care staff have traced the rise in intensive care from post-operative recovery wards in the 1930s (Conboy, 1947), to areas set aside for the care of patients involved in the 1942 Coconut Grove night-club fire in Boston (Fairman, 1992). The development of specific areas and technologies that provided pre and post-operative treatments for shock during the Second World War (Lenihan, 1979) are again an example of the concentration of the ‘sickest of a hospital population’. However like the development of mechanical ventilation, these were largely short-term strategies that did not necessarily obtain longstanding value, the technology was not durable (Latour, 1991).



Picture 3.4 Negative Pressure Ventilation (Iron Lung) in a distinct space.

The question remains as to whether intensive care is a specific space aside from the rest of the hospital, a specific set of practices, such as one-to-one care or a specific set of technologies, such as mechanical ventilation. Arguably, a Latourian reading may suggest that they are all crucial in the development of intensive care, yet the imagery invoked by a polio epidemic remains (see Pictures 3.3 and 3.4 above) as the lasting historical anchorage of the point of origin of intensive care. The polio epidemic is more *durable*, it holds because it reinforces a particular perspective of what intensive care is in the here and now. Both of these images are American, the first image, according to the Smithsonian National Museum of American History, was staged for a film and was not a functional ward. However, the significance of the Copenhagen epidemic is that they used positive pressure ventilation; that is the lungs were inflated as opposed to negative pressure (the 'Iron Lung'), where the body was encased in a negative pressure chamber, expanding the thorax and as a consequence doing the work of breathing inversely to the way that breathing is done in normal ambulant life. The image of 'Iron Lungs' remains durable in spite of it neither being a major feature of the Copenhagen epidemic, nor of the practices in the UK, it is an imagined image that remains durable.

Anaesthesia and intensive care.

Early anaesthesia within the US was often referred to as vocal anaesthesia (Ligon, 1936), performed by nurses and intimately bound with key feminine attributes, such as soothing (Fordham & Dunn, 1994; Smith, 1992), comforting (Morse & Johnson, 1991) and caring (Montgomery, 1993) which are seen to characterise nursing and its

public perception (Hallam, 2000). In order for anaesthesia to be legitimised as an arena of *medical* practice, these features associated with the feminine were replaced with masculine attributes of technology and control (Sandelowski, 2000) rendered possible through developments in pharmacological and manual ventilatory techniques (Hinds & Watson, 1996). This has been explained as a means whereby medicine commanded control over, and through positive pressure ventilatory techniques, penetrate the body (Sandelowski, 2000). However, the question remains over cause and effect (Heidegger, 1993) or, perhaps more specifically, concealing those attributes of anaesthesia allied to notions of femininity in order to reveal the development of anaesthesia as a masculine technico-rational discipline. Those aspects of health and medical care previously associated with 'bed-side' medicine (Foucault, 1973) being usurped by, among other things, the technical innovations of ventilatory techniques. This reading is contrary to the traditional reading of the consequences of developments in medical technology that gave rise to their utilisation by anaesthesia.

The development of Post-Operative Recovery Units has been cited as leading to the formulation of intensive care, particularly within a US context. They have been invoked in relation to territorial control, between anaesthetists (nurse anaesthesia) and surgeons, in addition to the clinical problems of post-operative physiological instability (Conboy, 1947; Fairman, 1992), reinforcing the tensions between anaesthetists, surgeons and nurses. The disparity that begins to emerge between the accounts of medicine, which places the rise of anaesthesia to the technologies available and the 1952 polio epidemic on the one hand, and that of nursing which places more emphasis on the distribution or concentration of resources on the other. Notably, medical students were used to ventilate patients in Copenhagen, the place of nurses falls more to the background as assistants to both medicine and students of medicine. These issues problematise accounts of the development of anaesthesia, as they do intensive care, an issue that will be broached later. The concealing could be seen as a specific device to subjugate the non-technical, arguably feminine work of nurses that in part demonstrate the cultural gendered inequality. At least this has been a particular, gendered reading (Fairman & Lynagh; Sandelowski, 2000) of the development of intensive care in the US. However, this is an issue that whilst of great significance, is taking the historical accounts to a point that takes them away from the major point of the thesis. The issues that will be the major focus within this research

centre around a specific space and its organisation and practice, not that of gendered divisions of practice. In addition, the issues associated with the development of intensive care are slightly different in the UK than a US context.

Within the UK during the nineteenth and up to the mid twentieth century, anaesthesia was performed by senior medical students under the direction of the surgeon, or by the surgeons themselves (whilst simultaneously performing surgery), and there was no training in anaesthesia within medicine, although it was an integral part of dental training and practice (Luke, 1908). When anaesthetists were employed they were dependant upon the attitude of the surgeon, who were frequently intolerant of anaesthetists. Luke (1908) highlighted some of the prevalent attitudes toward anaesthesia in his correspondence to *The Lancet*:

‘...an anæsthetist may be defined as “a latter-day nuisance of no use to the surgeon and a curse to the General Practitioner”...”there is no need more for an anæsthetist than for a hypodermic injectionist or other poisonist”

(Luke, 1908; p. 1108).

The first academic anaesthetic appointment within the UK was made in Edinburgh at the turn of the twentieth century, that of Dr. Luke, under the direction of a Professor Annandale, an eminent surgeon (Masson, 1988). However, Luke was not allowed any clinical role and simply acted as an instructor, his position being wholly dependent on the good will of surgeons and was relatively short lived, spanning less than 10 years. The position of academic anaesthesia became untenable upon the death of Professor Annandale, one of anaesthesia’s rare advocates in the surgical world (Luke, 1908; Masson, 1988). However, at the time of Luke’s letter to *The Lancet*, there was a great deal of political and public concern over the number of anaesthetic related deaths. This resulted in widespread discussion over specialist training, and indeed appointments in anaesthesia, vehemently opposed by some surgeons, and treated with indifference by the General Medical Council (Masson, 1988), medicine’s regulatory body. Indeed, a glance at Luke’s (1908) correspondence was a key insight into the attitude surgeons held toward anaesthetists at that time. One of the consequences of the employment of anaesthetists has been said to be the additional financial cost that would accrue, reducing the profit that hospital managers (senior medical staff) could make, in addition to the take home pay of surgeons. It was also felt that if anaesthetists were allowed into the operating theatre for ‘major’ surgery, then a ‘thin

end of the wedge' would be in place for them to legitimately practice in all surgery, something the surgeons and hospital managers would not allow (Luke, 1908; Masson, 1988). It is not just that there were financial issues concerning the appointment of anaesthetists, significantly their appointment challenged the sovereignty of the surgeon within the surgeons own realm. As such, it was not until the advent of the NHS that the role of the anaesthetist was certain and indeed nurtured (Payne, 1999). Even with the development of new anaesthetic agents and means of respiratory support, the role of the anaesthetist was restricted to that which occurred in the operating theatre. However, the advent of the new NHS provided anaesthesia with a *bona fide* clinical remit, albeit tightly controlled by the surgeon.

The intensive care unit as demonstrated in Copenhagen relied initially on manual positive pressure ventilation (performed by medical students in shift patterns 24 hours a day) as opposed to negative pressure exerted by ventilators such as the iron lung (Kesecioglu, 2000). The technology itself, in association with 'one-to-one' care made a major impact upon the survival of those with respiratory insufficiency (Lassen, 1953). The intensity of care also required a specific site within the hospital in which resources could be pooled and expertise concentrated, such as the previously depicted illustrations of the US dealings with the polio epidemic. However, as the polio epidemic drew to a close, the need for such specialised areas disappeared, and it was not until the 1960s that purpose-built intensive care units began to flourish within the UK (Woodrow, 2000). Once these rudimentary forms of intensive care (as they are frequently described) developed, medical and nursing staff were required to provide specialist 'cover' 24 hours a day, a key feature of contemporary intensive care. The anaesthetists' experience of the technology of ventilation and anaesthetic agents since the rise of the NHS in 1948 meant they were well suited to the contingencies of this type of work, which was not far removed from work in the operating theatre.

As the NHS came into being the place of anaesthesia was assured (Payne, 1999). Yet this space within the operating theatre remained the province of the surgeon to which the anaesthetist would remain subservient. The development of the recovery ward, such as those developed in the US in the 1930's provided a degree of autonomy for anaesthesia, but it was still 'the surgeon's patient'. With increasingly complex surgical procedures being performed, longer recovery times for patients ensued which

demanded a specific post-operative space prior to return to the general ward; the Recovery Unit. As previously noted in relation to the development of cardiac surgery in South Africa, intensive care units arose and were termed Cardiac Intensive Care Units which were designed to support the respiratory system of patients who had received coronary artery by-pass grafts. The space remained largely controlled by surgeons, in this case cardiac surgeons, and this form of intensive care could be said to have evolved as a form of Recovery Unit which dealt with specific forms of pathology, akin to those developed to meet the needs of patients with polio. Whereas a Recovery Unit dealt with all patients post-operatively, not restricted to surgical pathology, the Cardiac ICU provided care related to a specific surgical pathology and significantly, unlike the Recovery Unit, it provided one-to-one nursing care.

The intensive care unit which formed the basis of the field-work was split into two parts until the 1990's when one half was a dedicated Cardiac Intensive Care Unit and the other a General Intensive Care Unit. The Cardiac side was managed by the surgeons, whilst the General side by intensivists (consultants with specialist training in intensive care medicine) and anaesthetists who specialise in intensive care medicine. However, with the NHS reforms of the 1990's the Cardiac ICU became a part of the Cardiac Directorate and control was placed firmly back in the hands of the surgeons, a new specific intensive care unit was built in a different part of the hospital, on the other side of the Operating Theatre. During the period of this ethnography there was a tension between the surgeons and the intensivists, whereby the intensivists were asked to 'review' the surgeons' patients when they had multiple pathologies or were too sick for the surgeon to effectively deal with. The surgeons would in turn choose to ignore or act upon the recommendations of the intensivist. The intensivists then boycotted any review of the surgeons' patients because they felt there was no point in making recommendations that would then be ignored by the surgeons. However, they still accepted admissions of particularly sick long-term Cardiac intensive care patients, as they had ultimate control over the patient's treatment once in *their* (General) intensive care. However, after a number of arguments between the intensive care doctors and the surgeons on account of the former not following the suggestions of the latter, transfer of patients to the General ICU stopped.

A reversal of roles had occurred between anaesthesia and the surgeons and was contested in relation to specific spaces. This, as a position for the sickest (often long-term) patients within the Cardiac ICU, was seen to be untenable. As a result, the Anaesthetic Department that provided anaesthetic support for Cardiac Intensive Care, took control of the space of the Cardiac ICU, sharing responsibility for those patients with the surgeons. Significantly, the Anaesthetic Department had little responsibility for the General ICU aside from the allocation of junior doctors as part of their postgraduate medical training. Whilst tracing the development, locally, of Cardiac Intensive Care is of little concern for the ethnography, what it does demonstrate is some of those long-standing tensions between surgeons and anaesthetists and latterly, intensivists and introduces the politics of disposal of the 'intensive care patient'. Perhaps the space of intensive care, as historical lineages have attempted to trace it, could also be located as a professional struggle for the autonomy of a developing clinical discipline. Indeed, some intensivists within the field renounce their anaesthetic background, adopting a position quite critical of anaesthesia (particularly the Anaesthetic Department), and recasting themselves as specialists in Intensive Care Medicine, not Anaesthesia.

These tensions can be seen in relation to the differentiation between open and closed ICUs. An 'open' intensive care unit is common in the US and, as has been seen in relation to specific surgical ICUs, is characterised by a consultant having overall responsibility for 'their' patient, in the case of Cardiac Intensive Care, this will be a Cardiac Surgeon. That is whichever consultant the patient is admitted 'under', remains the consultant throughout a period of intensive care. Tensions such as those between the Cardiac ICU (surgeon) and the General ICU (intensivist/anaesthetist) are commonplace within such an environment. This is particularly the case as the professionals involved in the care of patients approach the treatment of disease from differing perspectives. This is commonly witnessed in relation to the point of withdrawal of treatment, whereby the surgeon may well wish to continue treatment whereas the intensivist feels that there is 'no potential for recovery'. Speaking to Cardiac intensive care staff, they suggested that patients who would ordinarily have died in the operating theatre are brought out to intensive care, something that does not happen within the field ICU. This, they suggested, is to do with statistics compiled which look less favourable on the surgeon if the death is peri-operative rather than

post-operative. However, it does reflect on the ICU, hence the field ICUs refusal to allow such an admission, particularly following the Bristol Paediatric Cardiac Surgery inquiry.

The significant difference between the 'Cardiac' and 'General' ICU is that the Cardiac ICU is 'open' whilst the General ICU is 'closed', the issues associated with open and closed ICU's is explored in more depth through Cassell's (2005) comparative ethnography of intensive care. A closed ICU, in short, is one whereby the responsibility for the patient is transferred to the site from the original (referring) consultant to (in this case) the intensive care unit and specifically to the intensive care staff. Visiting consultants, such as surgeons, are prohibited from prescribing drugs; they can make suggestions, but ultimately responsibility remains with the intensive care consultant and the intensive care staff. Within this ICU, the consultants work shifts that are a similar length to the nursing staff, so responsibility for patients' changes. The overall care of the patient remains organisational in some respects as responsibility is transferred from one consultant to the next during the unit handover, which is held each morning. So the patient, owing to this transfer of responsibility, becomes bound up with the space and the shift patterns of intensive care. Anaesthesia had found a home through intensive care, their own clinical domain whereby surgeons and physicians held an advisory role whilst the anaesthetist, and latterly within Europe, the specialised intensivist (who often had a background in anaesthesia) were responsible for the patients medical care. Perhaps this represents a reversal of Luke's (1908) position at the turn of the twentieth century; now anaesthesia and intensive care medicine have a specific space from which to practice and can dictate the terms of surgical or other medical involvement.

A number of caveats need to be raised in tracing the origins of intensive care as thus far illustrated. As for the inclusion of Nightingale (1997) and Alcott's (1863) descriptions of what is now referred to as triage, some nursing and medical writers take this to be the origin of intensive care. Whilst they may be distant relatives, they are equally related to practices in military medicine (Lenihan, 1979), accident and emergency (Huddleston & Ferguson, 1997), or indeed practices in general hospital wards whereby the sickest patients are located close to the nurses office (Latimer, 2000). Post-operative recovery units developed in the 1930s in the US and later in the

UK, and related specialised areas such as coronary care units pass a fleeting semblance to the contemporary intensive care unit. They provide specialised areas of observation and treatment in addition to specialised staff and the concentration of resources. However, the patient population is restricted to those who require a period of post-operative recovery from anaesthesia prior to discharge to the general hospital ward, or High Dependency Unit (HDU) on the one hand, to admissions restricted to those who have suffered an acute cardiac event in the case of coronary care on the other.

What differentiates the intensive care unit is that it does not discriminate admissions according to specific organ system pathology, but on organ system failure or failures. The Intensive Care Society agreed the criteria for admission to be based upon multiple organ system failure, or respiratory system failure necessitating mechanical ventilation which is potentially recoverable, and that the patient would benefit from such intensive observation and treatment (Spiby, 1989), as referred to toward the opening section of this chapter. Zussman's (1994) comment that intensive care is not a technology, but a place where technology is applied 'to the most intractable of medical problems' (p.19) may be a fair description of what intensive care might be in relation to this ethnography. What becomes clear however, is the work of othering, of alterity, the distinct separations that intensive care, through its staff, make between themselves (intensive care) and others (which is pretty much the rest of the hospital). In Zussman's terms they see themselves as the solvers of those 'intractable medical problems'.

Intensive care, and indeed many other health care environments, is suffused with technology, from surveillance and monitoring to therapeutic equipment. Observation has a close relationship to what intensive care does. Technologies, such as the thermometer (Sandelowski, 2000) and stethoscope (Foucault, 1973) have been the mainstay of physiological surveillance. Early incarnations of intensive care relied on these technologies, in addition to the technology of the health care professionals themselves who touch, feel, smell and view the sick body. Technology is not restricted to intensive care units, and those technologies ubiquitously found elsewhere were concentrated within early intensive care units, cardiac and associated monitors were not seen within intensive care units until the mid to late 1960s (Fairman &

Lynaugh, 1998), whereas mechanical ventilation remained a pervasive feature. The way that these technologies impact upon the practice of intensive care will be referred to in Chapter Nine. Interestingly, Sarah, one of the former Sisters from the field intensive care unit studied, relayed a tale of the first cardiac monitor they received, back when she was a new Staff Nurse. It remained in its box in the Sister's office, only coming out of its box and finding a way to a patient when Sister was on duty. When Sister was off duty, the monitor was off limits and woe betide anybody caught using it in her absence, be it medical or nursing staff.

Sarah: Looking back it was a bit pathetic really. All it was, was this little glowing blob that went across the screen. What with the PiCCOs and the monitoring and everything that we've got now it just makes me laugh. And then I realise how long I've been here ((laughs))
(From interview with Staff Nurse)

Notions of the development of intensive care have been aligned to numerous factors. It has been invoked in relation to the development of a distinct medical technology, namely mechanical ventilation and then to the use of this technology in an early form in the Polio epidemic of the 1950s. It has emerged as a form of triage system whereby the 'sickest' are treated in a specific environment. It is currently seen as being a distinct area of the hospital that ties it into the ubiquitously reported origins as the Copenhagen polio epidemic. It has been traced in relation to a distinct form of medical (anaesthetic) expertise, leading to the contemporary intensivist. This has been discussed in relation to post-operative Recovery Units that in turn differentiate the form of intensive care, whether it is a post-operative site dedicated to specific surgical pathology, or more generalist admitting any patient who fulfils the admission criteria. It has been invoked as a site of pooled resources and a means through which the most acutely ill can receive high levels of care and treatment. It has been related to one-to-one care and in relation to the fieldwork. It has even been referred to as a consequence of increasingly complex surgery and in relation to some of the monitoring equipment, albeit briefly. What has so far been left unsaid (and often is), is the work of nurses in the UK such as Dame Kathleen Raven, the then Chief Nursing Officer within the ministry of health who pushed forward plans to develop intensive care units. This was in opposition to the attitudes of the medical profession, notably the General Medical Council. Significantly, the intensive care unit became a space whereby patients were treated according to the severity of illness, not the individual pathology, with the

exception of some acute forms of respiratory disease that require mechanical ventilatory support.

Anaesthetics, whilst struggling for a legitimate clinical space through the first half of the twentieth century, found a niche in recovery units and later intensive care. While recovery units held patients for periods of hours post-operatively, the intensive care unit became the actual ward in which anaesthesia had found a 'home' to practice in. As the intensive care unit became a 'playground' for anaesthesia, innovative technologies such as cardiac monitoring, mechanical ventilation, renal replacement therapy, pharmacological agents could be tried and tested. The intensive care unit as a clinical playground rendered the patient and their pathology a bit of a 'science project' (Zussman, 1994, p.32). The utilisation of these innovative health technologies placed nurses and anaesthetists in close proximity, both groups were learning more and more about the application of clinical technology, trading knowledge and creating a highly technological environment (Fairman & Lynagh, 1998). These technological developments in turn created new ethical issues, such as when does death occur when the technological supports failed bodily organ systems (Beecher et al., 1968), when should such technological support be withdrawn, how is this withdrawal legitimated (Johnson et al., 2000) and in turn creating new iatrogenic pathologies (McKegney, 1966; Jones & Griffiths, 2002).

From the late 1960s (after the official development of intensive care across the UK) anaesthetists and intensive care nurses were involved in emergency call outs to patients throughout the hospital wards to deal with cardiac arrests. Whilst many hospitals developed their own specialised teams to deal with cardiac arrest procedures, leaving intensive care staff to remain in their own unit, recent policy changes (Department of Health, 2000) have led to intensive care nursing and medicine provision of an 'outreach service' for patients across the hospital. This not only involves the education of staff on the general wards, but the stabilisation and treatment of the critically ill who may have been, or may become, intensive care patients. The time of anaesthetists having no clinical role has now changed dramatically to them having a role that transcends the operating theatre, a move into the intensive care unit characterised by its technological resources, through to the assessment and treatment of patients on general wards that were traditionally the

vanguard of surgeons and physicians. As Carmel (2006) puts it, it was and is a form of expansionism or empire building on the part of the intensive care consultant.

Background to the Field.

The intensive care unit that informed this ethnography was purpose built as part of a wider development of a joint University Hospital (UH) and Medical School, opening in 1971. An intensive care unit also existed in the City Royal Hospital, the main city hospital prior to the development of UH, an eight bedded unit which closed in 1999 on the closure of the Royal. The intensive care unit in UH was set up as a medical-surgical intensive care unit taking both post-operative patients (in addition to those requiring pre-operative physiological optimization) as well as those with acute medical diseases. It was built with the Cardiac Intensive Care Unit next door (as previously mentioned) which took the cardiac surgical patients. The intensive care services being provided by the Royal catered for a whole spectrum of patients such as trauma, surgical and medical patients, with the city's Accident & Emergency department positioned there, however, in later years many of the more serious 'cases' were transferred to UH. The semi-rural General Hospital (GH) catered largely for patients with respiratory pathology requiring intensive therapy on the outskirts of the city. As part of health care restructuring brought about through the NHS reforms (DHSS, 1990), the health authority gained 'Trust' status and local services became centralised (Robinson & Le Grand, 1994), which could be seen as a euphemism for closure.

By this time the Cardiac ICU had been re-packaged under the managerial auspices of the Cardiac Directorate, leaving space for intensive care services previously provided by the Royal to be moved up to UH. Accident and Emergency (A&E) in the Royal was similarly relocated, but to a purpose built 'Emergency Unit' which took on board the University Hospital's Emergency Admission Unit (EAU) which took patients from paramedic crews in addition to General Practitioner referrals, far outweighing, in proportion of staff, the size of the EAU. At the time of the research the intensive care units had been amalgamated for over 5 years. As such initial problems of mixing staff, predominantly nurses (as all of the consultants (anaesthetists) from the Royal had left or retired), were not obviously evident, the new ways had been taken up by

the ICU staff, but some, such as Lotty, a senior staff nurse who had worked in ICU for almost thirty years put it like this:

‘You do get used to working differently, we [Royal staff] were made to fit in with the [UH] ways of doing things, but it just doesn’t feel the same up here, there is no time to do things with patients. I just think they don’t care...’

(From interview with Lotty)

The outlying GH escaped any such merger on account of being located within a separate NHS Trust. It did later come under the control of the Critical Care Directorate of UH, keeping its staff, but overall managerial control came from UH. As a result some practices such as continuous veno-venous haemofiltration (a subtle form of renal ‘dialysis’) and patients (the particularly sick) were forbidden, its patients more likely to be transferred to UH, should UH staff feel it beyond the skill and facility of GH. The ICU had been slightly downgraded; it came under the control of the UH Chief Consultant and was largely seen by intensive care staff as part of ‘his empire’. Back in UH, other changes were taking place, the surgical High Dependency Unit (HDU), run by the nurses and operated like an ‘open unit’ (as previously discussed) was increasingly altered to be more like the ICU, at least managerially. The medical HDU however, was originally located in a wing of the Royal that dealt with elder patients and its remit was to provide high dependency nursing care to patients who may otherwise not survive a transfer to UH, or would not be admitted on the grounds of age and multiple pathology. In its time and, to some extent, now in a time of rationing health services it offered a service to a group of people who may ordinarily be denied services on account of risk-benefit analysis, a fly in the face of financial healthcare discourse. It moved to the end of a ‘general’ hospital ward in UH, the gerontology HDU became a medical HDU taking a greater variety of adult patients of all ages.

The University Hospital is split into three main blocks, A, B and C. Each block generally houses two wards that are reached through a central corridor from which the wards split off either side at the end. The ICU floor initially held the coronary care unit (C Block) and cardiology ward, the Paediatric ICU (PICU), the surgical HDU and the haematology ward (A Block). The two intensive care units were located either side of the corridor on the B block. Having moved the haematology ward to another part of the hospital (which took up half of the block on that floor), the medical and

surgical HDU merged to become a general HDU (after the medical HDU had spent a temporary period tagged on to the space left by cardiac ICU on the north end of B Block) within a refurbished unit on A Block. Space had now been created to refurbish the north end of B Block (the space vacated by the Cardiac ICU) to become a specialised area for paediatric intensive care services, whilst the north area of A Block, having relocated the surgical HDU and PICU became a space for a purpose built extension to what had now become the Adult Intensive Care Unit, requiring the ICU to straddle two blocks (A and B as indicated in Appendix Four).

The now combined HDU took the space of the former Haematology ward. It was originally envisaged as open plan, similar to the new A Block ICU and the older B Block ICU. Gradually, the open nature of the combined HDUs was closed down until they were a distinct HDU managed by the ICU. The advent of *Comprehensive Critical Care* (DoH, 2000) following the Audit Commission report (1999), required a further collapse of services from specific units to patient need, requiring a further amalgamation of services so that a critical care unit is formed with a distinct mixture of expertise between those with a high dependency training and background with predominantly intensive care nurses and doctors. The HDU became almost an annexe of intensive care. Whilst *Comprehensive Critical Care* (DoH, 2000) required the abolition of the HDU into a combined critical care unit, this did not appear to work as well in practice. Senior Nursing and Medical staff attempted to outlaw the term HDU among their staff members. The HDU had intensive care patients admitted to reinforce the idea of 'Critical Care Without Walls' advocated by the Department of Health. However, over time, the HDU was referred to as the HDU again (it was less confusing for everybody), other staff such as visiting medical and nursing staff, porters and so on referred to it as a HDU, the porters even stuck to the older term of Medical HDU. The power of imposing this new terminology was demonstrated in an interview with a Staff Nurse from HDU 'everybody's allowed the odd slip', where the nurse felt compelled to almost apologise for referring to a HDU or ITU¹.

SN: Its trying to em, trying to forget all that's gone before and remember that you know its not HDU and ITU anymore its eh you know different areas within the same unit
Paul: So do you get corrected if you get it wrong

¹ Intensive Care Unit or Intensive Therapy Unit – the terms are used co-terminously, although the latter is generally used more frequently when describing 'other' units

SN: Em, at times everybody's, I think everybody's aware that its em everybody's having a hard time and everybody's got to try and do the same things em, so I think, you know if you accidentally let it slip you know your gonna go to HDU rather than I'm gonna go to the south side of the unit then um you know I think, I think your forgiven the odd slip, everybody's human everybody makes the odd slip at one point or another aren't they

(From interview with Staff Nurse)

The field work for this research was undertaken before and after this period of amalgamation and was intended to provide a comparative analysis. Following the amalgamation patients were no longer intensive care or high dependency patients but were classified according to their level of dependency:

Level 0	Patients whose needs can be met through normal ward care in an acute hospital
Level 1	Patients at risk of their condition deteriorating, or those recently relocated from higher levels of care, whose needs can be met on an acute ward with additional advice and support from the critical care team
Level 2	Patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those "stepping down" from higher levels of care.
Level 3	Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure.

Table 3.1 Dependency Scoring System (Adapted from DoH, 2000).

Unlike the disbanding of the term intensive care and high dependency in favour of Critical Care, these terms stuck. Patients were admitted as Level 2 or Level 3 and became a term of reference for an individual patient (other terms are highlighted in Chapter Seven). For the purposes of continuity, patients referred to in this research are classified for the most part as intensive care patients (Level 3) whilst those destined for HDU (Level 2 patients) are referred to as HDU patients. The areas are described as either intensive care or HDU, for similar reasons of clarity, particularly as the research material comes from both periods, unless explicitly mentioned by the informants. This brief outline of the local development of intensive care provides a context from which the local intensive care unit can be understood. The historical

accounts and recourse to secondary historical materials on the other hand provide a context from which intensive care can be understood as a distinct medical concept, a site of accomplishment. For the final section of this chapter a brief outline will be presented into how the intensive care unit and the idea of intensive care is presented through the popular media.

Representations of Intensive Care.

Standing at a bus stop, waiting for a bus after a period of field work, a bit of a walk from the hospital (as it was a cheaper fare zone), I unintentionally (at first) eavesdropped on two women chatting. The first told of how her husband had been in intensive care for two weeks, he was on the ward now and much better. The second lady replied that her daughter had been in intensive care, to which the first responded that her husband was *really poorly*, he was on the 'critical list'. 'So was my daughter' the second responded, 'and she had a tracheostomy in her neck', as though she had just trumped the illness of the other woman's husband with the tale of her daughter. The bus came and I knew no more of the husband and the daughter, I didn't recognise the women from intensive care either. However, the tales of their husband and daughter provided them with a certain cultural currency that could be invoked for some reason; being or being close to an inhabitant or survivor of intensive care gave them a certain initiation of a discussion. This section of the chapter, in part catalysed by the two women, provides a short presentation or (re)presentation of intensive care as portrayed in the popular media. The intention is to offer a wider cultural account of what intensive care might be and what, through its invocation, it accomplishes within such media, beginning with a series of newspaper headlines.

'Hamster's fast recovery; Top Gear star is out of intensive care after horrific 300mph crash'
(Sunday Express)

'Soccer star in intensive care'
(Daily Mail)

'Flying dolphin puts boat woman in intensive care'.
(Daily Mail).

'BREAKING NEWS... Biker in intensive care after crash'.
(South Wales Argus)

'Murderer is still in intensive care'.
(South Wales Echo)

'He wanted to die with a sword in his hand, but a butterfly knife was the best we could do in intensive care'.
(Hull Daily Mail)

'All the family were there in intensive care, like Orpheus waiting for Eurydice'
(The Independent on Sunday)

'Sick patient HSBC out of intensive care, but only just'.
(The Daily Telegraph)

'M&S comes out of intensive care - but is not yet fighting fit'.
(Financial Times)

'Accounting blows that put iSoft into intensive care: Suspensions, inquiries and plummeting shares have battered the software firm and hurt its biggest client - the NHS'.
(The Observer)

'GCap puts Capital in intensive care over Heart attack'.
(Independent on Sunday)

'Peace process in intensive care: Hopes for an end to violence in Israel may not be dead but, says Eric Silver, the latest setback as a result of the suicide bombers has left it in a critical condition'
(The Herald [Glasgow]).

'FARC says peace talks in "intensive care" due to Plan Colombia'
(Belfast News Letter)

Through a brief analysis of newspaper headlines over the past ten years from LexisNexis, intensive care appears to cover four main types of story. The most prevalent are those concerning those people in the public eye, such as television presenters, singers, actors or sports personalities who have been admitted to intensive care, such as the top two examples above. Those who are admitted following a particularly quirky accident, such as the 'flying dolphin boat woman', or the dramatised 'BREAKING NEWS' of the motorcyclist also feature. There are examples of wrongdoers such as murderers being present, and the victims of wrongdoers, all of whom refer to people admitted to intensive care and for whatever reason are felt to be newsworthy. There also exist accounts of those who have been with others in intensive care, such as the man who wanted to die with a sword in his hands. Tales of coming out from intensive care are akin to coming out from another world, invoked in reference to ancient Greek mythology.

These references to intensive care, just taken from headlines, have quite powerful imagery associated with them. Whilst there are quite frequent accounts of intensive care and its associations with the dramas of human life, there are also quite a few

which are associated with business. Headlines concerning debts such as the bank HSBC and the high street store Marks and Spencer, financial irregularity regarding a health care software company and the decline in listeners to a radio station, Capital Radio. The last two quotations presented concern peace talks and whilst less commonplace than the others give an idea of what intensive care represents within a popular consciousness and how the notion of intensive care is mobilised within this particular form of popular media.

If a discursive analysis was used, the headlines would probably signify a swing in opinion between the deserving and undeserving intensive care patient, the murderer and the victim, and it wouldn't take long to find some moral stance that bends the discourse in a particular way (Lupton, 1993). Ideas of the relative worth of businesses, whether they deserve sympathy for the state they are in or not and that peace talks are always deserving of intensive care, or suggestive of a serious breakdown in such talks. Other newspaper headlines have emphasised the spread of infection into intensive care and pressure on intensive care beds, particularly during the 'winter crisis' of 2003. However, a thorough discursive analysis is not the aim here. What is significant is the mobilisation of a particular metaphor of liminality, particularly between life and death, of persons, of business and organisations and of a period between peace and war. Intensive care is mobilised for its imagery in a popular mindset as a cultural material. For many visitors to intensive care a frequently heard comment is 'its amazing what you can do with all this technology these days', and this technology can be associated with a kind of hope, the last chance of resuscitation, not just of bodies, but of situations and organisations that are deserving of the fullest 'treatment' available, and conversely 'undeserving'. As a particular social space, intensive care invokes imagery of seriousness, of drama, of betwixt-and-between, of life and of death, it demands to be taken seriously and the headlines demand that the situations they describe be similarly taken seriously.

The space of intensive care in these headlines is a particular space of liminality (Turner, 1970). Not simply a physical space or a metaphorical space, but a space of invocation (Bhabha, 1994). These news reports demonstrate a multiplicity of situations through which intensive care can be invoked. Paradoxically through this invocation, in re-casting the metaphor of intensive care, a singular narrative comes to

the fore. That is, while there are multiple ways in which intensive care can be mobilised as a metaphorical device through the cultural performances of a newspaper headline a singular perspective of intensive care is produced. This perspective is one that has common currency in a broader culture that many would not have first hand experience of, yet a common understanding of proximity to death, technology and medical expertise is produced through these metaphors. It is argued that a space of liminality, a cultural space that perceives itself as distinct from the rest of the hospital (as in the previous sections of this chapter) is reinforced by such a metaphor. Intensive care becomes a trope for the tragic, of justice and injustice, of a space on the edge (Turner, 1970; Fernandez, 1986). These ideas come from newspaper headlines, but intensive care is also invoked in popular literature, and provide a slightly different notion of what intensive care is all about, particularly with regard the space of intensive care.

‘...A surrealistic alien environment emerged...usual sounds like voices and footsteps were muted...Mechanical and electronic noises dominated, particularly the rhythmical beep of the cardiac monitors and the to-and-fro hiss of the respirators. The patients were in separate alcoves, in high beds with the side-rails pulled up. There was the usual profusion of intravenous bottles and lines hanging above them, connected to impaled blood vessels by sharp needles...A few of the patients were awake, and their darting eyes betrayed their fear and the fine line that divided them from acute insanity...’

(Cook, 1977 p.48).

In Robin Cook’s book, *Coma* (1977), a specific vision of intensive care is created. It is an imagining of intensive care as a space deserving hushed reverence, set aside for the beep and hiss of medical technology. It is painted as a space in which hazards exist for the conscious, the unconscious are spared. It is a space of fear that places the conscious at a point close to mental unrest. For those who have written about their experiences of being in intensive care (Watt, 1996; Reeve, 1999; Robillard, 1999; Richman, 2000; Rier, 2000), the perhaps overly dramatic writing of Cook has some resonance. Robillard (1999) made reference to feeling like one of William Gibson’s (1995) cyberpunks, whilst Richman (2000) could only write about intensive care in reference to the nightmares and all of them experienced some form of anger as a result of being within intensive care. However, these issues will emerge through the ethnography proper, yet another idea of the space of intensive care has been presented, and its necessary for another, final, imagining of intensive care.

‘...ever-shrinking hands reduced to talons; clear plastic IV drips like boil-in-the-bag dinners gone badly wrong; an iceberg blue respirator tube connected to the core of the Earth hissing

sick threats of doom spoken in another language; hair always straight, combed nightly, going gray with the years; and limp as unwatered houseplants...'

(Coupland, 1998, p.25).

Images of the vulnerable intensive care patient are seen frequently within popular literature, such as Douglas Coupland's account of a comatose young girl within the intensive care unit. The Intensive Care Unit, as such, is a symbol of mortality and the stark severity of illness and injury within contemporary culture that plays on that which has not yet happened; death, injury or survival. The presentation of the ICU guides the reader into the realm of the serious nature of the illness or injury, and its consequences. Such imagery invoked in descriptions of the ICU, such as the preceding quote by Coupland, largely speak for themselves, the physical decay, horror and hopelessness being poignantly evident. This symbolic representation of the ICU can be viewed as representative of a contemporary equivalent, although arguably less dramatic equivalent, to previous literary associations of mortality and severe illness, underscored by the image of the 'sick bed' (Tolstoy, 1960) and the imagery of home, and the Sanatorium (Mann, 1999). Perhaps similarly significant is the characterisation of the ICU, or indeed any symbol of mortality, within an 'other worldliness' as noted in the newspaper headline relating the experience to that of Orpheus and his wife Eurydice. This notion of being 'somewhere else', or as Sontag (1991) put it, inhabiting '...the kingdom of the sick...' (p.3).

Within television and film, intensive care does not play such a large role, its use as a metaphor becomes slightly less interesting in the flesh. Episodes of medical dramas such as the US program 'ER' pan to the faces of loved ones and briefly to the faces of the critically ill attached to a ventilator. It is something referred to more than located in. The UK based series 'Holby City', tends to ignore intensive care patients, when they are a part of the scene. They are generally only focussed on when the endotracheal tube (breathing tube to facilitate mechanical ventilation) has been removed which allows them to speak during the scene, unless they are about to die, in which case they can be portrayed as a face with eyes about to close as a symbol of death. The intensive care unit may be hushed and reverent (occasionally), but that does not make the space good television, irrespective of the metaphors associated with it. During the period of fieldwork a film crew arrived in the ICU to produce a program about Dylan Thomas's 'Do Not Go Gentle Into That Good Night' and based

it upon intensive care as a metaphor for fighting against death, fortunately for them they did not require any ethical approval. After interviewing a consultant and a few of the nurses, they asked if they could take an 'action shot' of what it was that intensive care doctors and nurses did when on duty. They were told that what they saw was pretty much it, they responded that they could be doing something, like preparing some piece of medical equipment. None of the nurses were keen on playing the role of nurses, so in the end they filmed a nurse drawing up a syringe of drugs which was never screened. The film crew looked quite disappointed really, but as many intensive care patients have put it, it is a very boring place. Suffice to say as a distinct cultural material intensive care is invoked as a metaphor for vulnerability, of suffering, of liminality and the pinnacle of medico-technical accomplishments.

So What? On multiple representations of intensive care.

The aim of this chapter is to provide a multiplicity of accounts about what constitutes intensive care. The first section, for the most part, concentrated on the perceived origins of intensive care. One of the key features of intensive care in the present is mechanical ventilation, and this technology has been traced from Vesalius to the bellows of the Royal Humane Society to the concentration of negative pressure ventilators (Iron Lungs) in the US and significantly the use of manual (positive pressure) techniques in Copenhagen in 1952. It is through the treatment of patients with a similar prognosis in a given space with a form of positive pressure ventilation that provides this particular historical anchorage with durability (Latour, 1991). The criteria for admission to intensive care (which is also the definition *of* intensive care) in the present fits neatly within this means of ventilating within a particular space that ensures that this particular history holds, at least among intensive care professionals with an interest in its origins.

Yet the idea of concentrating the sickest of the hospital population in a certain space is not that new, perhaps predating the accounts of Alcott (1863) and Nightingale (1860, 1997). A more gendered reading may suggest that because these commentators are female and were referring to work associated with a female workforce may render it easier to disregard. Particularly as a medical account could be seen as more dismissive of the work of nurses, or a nursing account of the origins of intensive care,

or at the least a form of triage. But this is a moot point, as triage became an established part of hospital practice (and still is) long before ideas of placing ventilators in a certain space was considered, the significance of this point of origin rests upon a concentration of the most sick, not the technologies which sustained them. The development of post-operative Recovery Units similarly does not rest upon mechanical ventilation, but they are heavily associated with anaesthesia and the meanings of anaesthesia and anaesthetists in particular are quite different in the UK than the US, where such units developed.

When the development of anaesthesia is traced, which has a distinct relationship to intensive care, the rise of intensive care emerges slightly differently and slightly apart from the Copenhagen polio epidemic. It has more to do with the development of a neophyte medical discipline that is breaking free of its dependency upon surgery for its livelihood. From the advent of the NHS, Recovery Units on the one hand provided the anaesthetist with a certain space in which to practice. The development of intensive care on the other hand provided the anaesthetist with a great deal more clinical autonomy, a space of stability, free from the dependence upon the surgeon. The opinion of Professor Payne, an anaesthetist, suggests that it was both nursing and anaesthesia that gave rise to intensive care as they were in similarly subjugated positions as health care professionals, advocating for the intensive care unit together. Yet the advocate in the form of the Chief Nursing Officer within the then Ministry of Health receives little recognition from intensive care 'historians'. Nevertheless, a bifurcation appears between the forms that intensive care should take, on the one hand with the development of cardiac surgery extending the concept of the Recovery Unit and including forms of mechanical ventilation, whilst the other 'closed' the intensive care to a great deal of 'surgical interference'. The former intensive care site retains its anaesthetists whereas the latter has led to a new breed of doctor, the specialist in intensive care medicine, or intensivist as they are known. Intensive care medicine became a discipline dedicated to a particular space, the intensive care unit, then the High Dependency Unit, then the hospital and with the push toward follow-up and retrieval services, the community at large.

Another core feature of the contemporary intensive care unit is the surveillance technologies. However, as the former Sister, Sarah, demonstrated the technologies

available weren't treated particularly seriously by the Sister, keeping the only oscilloscope away from general use. Critically, the monitoring equipment in part defines what intensive care accomplishes as medico-technical space. The site locally was presented as a site of political contestation, an issue that will re-emerge in Chapters Seven and Eight. Suffice to say, intensive care emerges as a site of developing clinical autonomy, particularly in relation to the specialist expertise required in working the specialised technology of mechanical ventilation. Again this ties back to the durability of the technology and the space as suggested through recourse to the polio epidemic. From this point a representation of the field site and its expansionism, the closure of the 'other' ICU and the conformity to a certain way of 'doing intensive care' as Lotty suggested. More recently, the 'not speaking its name' mentality of ensuring that intensive care and high dependency are replaced through the policy developments leading to 'critical care' have been alluded to. For the intensivist Saxon Ridley, this is a political move following successive intensive care 'bed crises' that allows the government, through reclassification of intensive care and high dependency into 'critical care' to provide sufficient critical care beds at the expense of intensive care beds. The move is legitimated as they have 'x' number of additional 'critical care' beds now, yet the number of 'intensive care' beds has remained unchanged. Of course patients have been reclassified according to dependency levels to ensure the right body is in the right bed space so that Critical Care works (a presentation of beds and bodies will be made in Chapter Seven). However, this has been at the same time the death of intensive care itself and, following the manner of many deaths that occur in intensive care, it has been a silent one.

What is being reproduced here is intensive care as a concept of durable space, one that is contested in the day-to-day life of intensive care. Even though as a political concept in relation to the spatial elements of intensive care, specialists in intensive care medicine remain and the imagery associated with it continues. Within the newspaper headlines 'intensive care bed crisis' disappears in relation to Adult or General Intensive Care Units, it remains in relation to Paediatric Intensive Care as Adult Intensive Care is usurped by the idea of Adult Critical Care. Yet the imagery of intensive care remains, it is an image that demands attention, it needs to be taken seriously. Whether the image is invoked in relation to a celebrity illness or injury, a

quirky incident or one that involves victims or perpetrators of crime, the seriousness of the situation for those concerned remain. Beyond this intensive care is a situation that peace talks find themselves in when they don't go to plan (from a certain perspective) or businesses fail. The imagery of intensive care is a contemporary metaphor for proximity to death, at least as portrayed within newspaper headlines and not far removed from older associations with a point close to death, yet with a possibility of survival. The criterion for admission appears again as a means through which intensive care can be reproduced, culturally. Another means through which intensive care's definition of itself maintains durability and it is argued, a durable space of invocation (Latour, 1991; Bhabha, 1994).

Whilst intensive care has multiple points of reference to gain a foothold into what it is, it is understandable given the literature of the medical crime drama and heuristic accounts that intensive care becomes a little darker as a space. The more positive notion of intensive care representing situations that one of the staff members termed as FUBARBNDY'D (Fucked Up Beyond All Recognition But Not Dead Yet), a term which refers particularly to patients with multiple organ failure, who are wholly dependent upon supportive technologies and drugs, would ordinarily have died but are at the edge of life and death. Whilst a vernacular term which is not commonly used among staff and never among 'other' non colleagues or the unfamiliar, within this 'not dead yet' there remains some hope. Perhaps what is significant about intensive care in these representations is for the most part they offer hope, for some there should be no hope, but its there all the same. It is a space of human drama, but as a cultural space it is incredibly dull (Zussman, 1994). This introductory invocation of intensive care from a variety of sources is aimed to provide an educated immersion into intensive care, about what it is does, what it accomplishes socially and a platform from which the thesis is based. The next chapter (Chapter Four) will outline the methods used in the performance of this ethnography, which are intimately tied to the epistemological/ontological position set out in the previous chapter. As ethics, at least in a bureaucratic form, has had such a major impact on this research, the issues that emerged through the conduct of this research will be dealt with in Chapter Five. So for now we are discharged from intensive care, it has been disposed of, yet will return.

Chapter Four.

On Performing Method.

Introduction.

For over eight years I have had a close involvement with intensive care, as a nurse and as an ethnographer. As a nurse I had the feeling that something was missing from accounts of intensive care, but not quite knowing what. Becoming familiar with intensive care literature it became increasingly apparent that little was known about the patients in intensive care, or more particularly, the patients that survive intensive care. The missing voice of the critically ill, as Rier (2000) put it, is a voice that is largely absent from sociological enquiry and from the enquiry of health care professionals. When the voice emerges, it comes from the perspective of an individual at the receiving end of intensive care therapy. It is from the perspective of those who have engaged with intensive care at an end visible point, the point of display of intensive care.

As made clear within Chapter Two, that which I took to be crucial within this research was the location of certain narratives of intensive care, discursive practices that in part shape and create the performative display of intensive care. The assumptions that underpin this display could be used as a means through which the accounts of the survivors and the families of the critically ill could be understood. The intention then was to analyse such accounts through the cultural practices of intensive care staff and their tethering to health care policies, local politics and medical technology. This appeared to be a worthwhile means through which the front of house display and the backstage (Goffman, 1959) discursive practices could critically engage with the accomplishments of intensive care and the effects such accomplishments hold over those who pass through it.

This is the position from which the research began, a position of engagement with research at the point of both ontological and epistemological consistency. Such a position takes the conduct of research seriously, however, this was not what was required of the Local Research Ethics Committee and as a consequence the research

as envisaged was not conducted. Some of the ethical issues and problems associated with performing research within intensive care will form the opening section of this chapter. Initially, as referred to in the Introduction (Part One), the research aimed to perform a series of follow-up interviews with patients and family members following discharge from intensive care. However, the crippling delay in receiving ethical approval meant that this could not be achieved. Instead an ethnography of the space of intensive care was conducted. The original proposal submitted to the ESRC also involved a constant comparative method (Glaser & Strauss, 1967) across two research sites, which was originally intended to be the University Hospital (UH) and the General Hospital (GH) intensive care units (as referred to in Chapter Three). The Chief Consultant, however, felt that the two sites were not comparable as the second site was, in his opinion, an intensive unit for the less seriously ill; 'a lesser ICU'. Given his connections with intensivists around the UK, he secured approval from the Chief Consultant of another intensive care unit which was about fifty miles away to perform the research. He felt that another University Hospital ICU would be more comparable. In turn I secured research funding from the British Association of Critical Care Nurses to cover the costs of accommodation and travel whilst performing the research in the second site. Again, this aspect of the research never materialised as I wished to secure ethical approval for the first site so that I could compare the ethnographic material with the second. So the second section of this chapter provides an account of the research as conducted, detailing the process of securing consent, predominantly from patients within the field.

The third section of this chapter highlights the important role of gatekeepers within the research. Gaining allies was crucial in allowing the research to be conducted in the first instance and even made the securing of ethical approval from the LREC possible, when finally invoked. The fourth section of this chapter will provide a brief account of how the ethical problems associated with the performance of research in intensive care were broached. A particular way of dealing with problems of ethics was built in to the project from the outset, as previously mentioned, and some of these issues will be addressed more thoroughly here. A separate chapter on ethical approval, as it became such an over-riding part of this thesis, follows this chapter and so will not be discussed here. Those aspects concerning the 'nuts and bolts' practicalities of performing the research have been documented toward the end of this chapter. It is a

'real-and-imagined' (Soja, 1996) representation of what research was performed and what was unable to be performed. So the aim of this chapter is to tie in those issues concerning methods with the epistemological position and accounts of intensive care as outlined so far, enabling a position to be drawn from which the ethnography proper could be understood.

On Getting into the Field.

From the very beginnings of this project I had been required to perform certain functions in order to satisfy particular stakeholders that the project was viable, valuable and legitimate. This required a liaison with certain people in order for the project to commence. Involving these key stakeholders, such as consultants (particularly the Chief Consultant and his deputy), managers (particularly the Clinical Nurse Manager) and the hospital Research and Development department as well as workers in the field was imperative to the success or failure of the project. As the research involved critically ill patients and their families and as they were not consulted about the research in the design and formulation of the project it was vital that those key stakeholders were aware of and had endorsed the project. This was particularly important given the serious nature of the illnesses and their treatments whereby those stakeholders acted as advocates on behalf of those patients and families who would be involved in the project in the future. It became necessary to satisfy the requirements of those individuals, who for the most part saw the research as a positive thing in that it would provide certain benefits for them. These were of particular significance to the Chief Consultant of the intensive care unit who felt that having a research student in his department was a good thing in its own right. 'His department' would gain some benefits from presentation of the work and as he and the senior nurse manager stated, would aid in recruitment of staff as the research could be highlighted as something that the department was keen to develop.

This aspect of recruitment was seen as of great significance as there was a great deal of difficulty in recruiting highly trained critical care staff (particularly in medicine and nursing) and at a time when research itself was seen by both government and professional bodies as a key aspect of trainee intensive care doctors and senior intensive care nurses work. This has since changed, at least in medicine, under the

new medical training policy 'modernising medical careers' (DoH, 2004) and is no longer a requirement for trainee intensivists, whilst it remains an aspect of the Nurse Consultant role. So in some way it was seen as a means through which the 'flag' of this particular intensive care unit could be flown on a national and international stage. This was seen as a mutually beneficial relationship between the department and myself, as viewed by the managerial face of the department; the senior nurse and senior doctor.

Through informing the intensive care staff (the Chief Consultant in particular) of the background, rationale and aims of the study I had gained an ally (Latour, 1987). Having stakeholders as allies at this stage of the project certainly enabled the project to have a good chance of being successful. Not only did they enable the pilot study to get through barriers such as the LREC with relative ease, but as the main project was being put to various bodies they put their name to different forms, ultimately taking responsibility for the project within their own area of practice. Whilst discussing the submission of the project to scrutiny by the R & D department, the administration staff pointed out that I would need an honorary contract before a final decision could be. This was because I was neither based within the NHS or the separate College of Medicine (as it was then). These organisations as previously outlined (Chapter Three) were closely linked, both physically and organisationally. I however, was based in the University, which has since merged with the College of Medicine. This advice meant that I could make a start on securing a research contract without having to resubmit an application to them. Whilst it took a while for the research contract to be formalised as there had been no non-medical researchers within the department and medical researchers themselves generally had a contract with the NHS Trust anyway it took time for the particulars to be finalised between the Personnel Department and the ICU management. However, the support of the management team made such a contract possible in the first instance. With the support of the Chief Consultant and lead research consultant for the department, the application was risk assessed and passed first time, with no amendments required. In part, this emphasises the role that powerful allies have in ensuring that research makes it through to fruition.

So for the first pilot submission, I had the Chief Consultant documented as Principal Investigator (P.I.), Dr. Latimer and Prof. Williams (my supervisors) as co-researchers

and myself as an on-site researcher. I was employed by the Intensive Care Unit that was the site of the study and had experienced researchers within the School of Social Sciences 'overseeing' the investigation. The Research Nurses based within intensive care assisted in the adjustment of the research protocol as originally envisaged, to fit the format of the COREC (Central office of Research Ethics Committees) guidelines. They had copies of 'model' information sheets and consent forms that formed the basis of the actual information sheets and consent forms and helped assimilate the new research protocol to fit the format for the LREC application. As they had been through this process for the numerous drug and equipment trials within the unit, the Chief Consultant pointed me to them for help and assistance with the research. Having some powerful allies documented on the forms, being employed by the NHS and the particular ICU rendered outright rejection of the research by the LREC more difficult. The research was legitimate in the eyes of the LREC, not just because of the allies but the 'scientific tone' of the application. The issues concerning ethical approval in the second instance are dealt with in the following chapter, so will be omitted here.

Research problems in intensive care and the problem of ethnography.

Conducting research within an intensive care unit is problematic. This is the case with Randomised Controlled Trials of new drugs and technologies that often require assent (proxy consent) from family members at a time of great distress. The difficulties are heightened in non-clinical forms of research whereby the immediate benefits are less than obvious in the long or short term, or even if there can be no substantiated benefits at all. For example, in one survey of 817 patients who had been intubated within the ICU (Rotundi *et al*, 2002), 667 patients were lost to the study. This large attrition rate was due to death, fatigue, medical and psychological morbidity and discharge from hospital prior to the survey being conducted. This left the researchers with 150 patients of whom 50 did not recall being within the ICU at all. The problem of attrition would seem to be a feature of research within intensive care. On the face of it, the problems would seem to be heightened in ethnographic research, particularly one that aimed to gather accounts of intensive care from surviving patients and their families. From the initial pilot study, three of the six informants were unable to give follow up interviews; one of whom died, one was transferred to another hospital and

the third was too fatigued to continue. Two of those involved were not part of the field study period and one detailed her experience from over 10 years previously. The second was inadvertently recruited to the study after being discharged from intensive care to the High Dependency Unit, as one of the consultants suggested he talk to me about his experience. He later refused to have the interview tape recorded. As such, only one patient was interviewed following discharge from the intensive care to the ward.

The second part of the study fared even worse, intensive care was uncharacteristically quiet from August to September 2005. The Chief Consultant found this highly amusing, particularly as he had been involved in helping to secure ethical approval, at least when he was present and able (see Chapter Five). The task I set myself was to enrol those patients who were likely to be intubated for greater than seventy-two hours and were likely to survive intensive care through to being discharged home for follow up interviews with themselves and their family. Those intubated for greater than seventy-two hours are seen to be more likely to develop physical and emotional consequences than those intubated for lesser periods. This was felt to be crucial in developing an understanding of the impact of intensive care practices upon intensive care patients and their families, and was a key part of the initial research protocol (see Appendix One). During the three months I had to perform the research only a handful of patients were eligible, none during the first four weeks within an intensive care unit that admitted (through 2004) 2,300 admissions. The patients were either going to be admitted in terms of months, which was too long for the length of time left to perform the research, they had already been admitted some time ago, or they had developed severe emotional problems and contact with me was viewed as inappropriate or they had been discharged from the Directorate (Critical Care).

By the close of the field-work, I had recruited five patients to the study when the intention had been to recruit ten to fifteen through to discharge and follow up. Of the five patients and families that I followed through their stay within intensive care, only one was available for follow up interview and this occurred through serendipity more than careful planning. One of the contributing factors was the way in which the organisation of intensive care held responsibility for patients through the consultant on for the shift. I was a regular follower of the Ward Round, as was Zussman (1994),

of which there were three, one for each side of the unit. I sat through the main handover between the consultants, so gaining consultant approval was not a problem. However, once the patient had been discharged from the Critical Care Directorate to the ward, I had to gain approval from the patient's receiving consultant to interview them. This in all but one instance was virtually impossible as they appeared to spend most of their time off the site, if I contacted them via the bleep system, they were too busy to talk to me and were not at all interested in an 'intensive care issue'. Following up this one patient on discharge to the ward, I discovered his location from the ICU admission and discharge book. I attempted to visit, but he had been transferred to a different ward, the Nursing Assistant at the ward reception desk told me that she was busy and if I came back later (presumably when the receptionist returned) I could find out where he had gone. I returned to intensive care and asked the receptionist to find out where he had gone, she found the correct ward that he was discharged to, only to find out that visiting time was over. However, I showed my ICU identity card and was told where to find him. This particular patient found talking quite tiring on account of his breathlessness, so the interview was abandoned.

As amused as the Chief Consultant, a couple of the consultants and quite a few of the senior nurses were with the way the research was going, the problems of performing the research really hit home, particularly in light of problems securing ethical approval in the first place (as is highlighted in Chapter Five). But there are a number of issues that make such research quite difficult, particularly given the inclusion criteria for this research. These did not raise themselves as problems during the pilot study, only emerging as part of the main research. Predicting outcomes from intensive care has been a particular focus of research over the past twenty years within intensive care, particularly by the Intensive Care National Audit and Research Centre. However, it has proved quite difficult, even though increasing numbers of variables and increasingly sophisticated tools have been introduced, it remains difficult to predict outcomes from intensive care. The average cost of an intensive care bed for a patient per 24 hour period is £850 (Edbrooke *et al*, 1995; Jacobs, 2004), it is seen to be more in University Hospitals (Flaatten & Kvåle, 2003) and the hospital that permitted this research would put this closer to £1000 as one consultant suggested. For an ICU that has 18 beds, there is a financial incentive to predict outcome of patients who are likely to survive intensive care. If with such an incentive it remains

difficult to predict, then it should be unsurprising that a research student similarly has difficulty in predicting patient outcome for enrolment of patients into an ethnography, particularly when patients are transferred to other hospitals and so many other consequences of intensive care impact on these patients' willingness to take part.

There are specific physical and emotional effects that people experience as a result of treatment within intensive care. These include, but are not restricted to, post traumatic stress disorder (Michaels et al, 1999), acute stress disorder (Vick & Roberts, 2002), depression (Perrins et al., 1998), insomnia, limited mobility, breathing problems, swallowing problems, chronic itching (Waldmann, 1998), relationship problems, loss of memory and fatigue (Griffiths & Jones, 1999). The list of consequences of receiving intensive care treatment is quite large, some of which are short term problems whilst others may remain, having an impact upon the life lived outside of intensive care. These issues are related to the treatments, such as mechanical ventilation, large periods of immobility, particularly among the longer term patients and of course the pharmacological agents used within intensive care such as anaesthetic drugs and drugs to maintain cardiovascular integrity. However those that survive have a similar long-term mortality to the general population, after controlling for the effect of hospital admission (Keenan et al, 2002), yet the chronic health problems associated with treatment within intensive care, such as those listed above are numerous and widespread. This led to a greater level of difficulty in recruiting patients to the study, particularly for follow up interviews.

Intensive care is an arena fraught with ethico-legal implications of advancing technology. The most dramatic are those such as the nature of death when organs still function, or are supported by therapeutic intervention, as in the case of brain stem death (Beecher et al., 1968), or those concerning a persistent vegetative state (Airedale NHS Trust v Bland, 1993). The ICU is associated with a high mortality rate among its patients, with up to 90% of those patients that die in the ICU, doing so as a result of withdrawing, or withholding supportive therapies (Prendergast & Luce, 1997). The withdrawal and withholding of treatment is partially constituted through the discursive recasting of the life saving medical technology as a technology that prolongs death (Johnson et al, 2000). This illustrates to some degree the ambivalent attitude toward technology held by the medical professionals that use it (Zussman,

1994). It demonstrates the paradox of 'mastering disease', and the recognition of a new domain within healthcare, that of medical futility. But as previously noted, predicting the point of futility prior to admission is not easy, the point of futility emerges once the failed organ systems are recognised as permanently failed with no possibility of recovery. And this point of futility is discursively constructed after the event, once the discourses of supporting failing organ systems has failed. The emotive nature of intensive care, as it involves in many instances the futility of treatment, adds to the difficulty involved in performing research there.

As part of the ethnography proper within intensive care, there are particular issues that make performing interviews more difficult. The most obvious relates to speechlessness which is a consequence of the mechanical ventilation. Endotracheal or tracheotomy tubes which facilitate such ventilation, can cause pain and discomfort among intensive care patients (Jablonski, 1994), the former greater than the latter. Within intensive care, patients have also reported the experiencing of an altered sense of self, encompassing alienation, disorientation, fragmentation and displacement (Jenny & Logan, 1996). The pharmacological restraints used by intensive care staff lead to amnesia, with whole days and weeks being unaccounted for by patients (Jablonski, 1994), the environment itself has been referred to as a 'panoptic dream' (Robillard, 1999, p.49), with many patients experiencing unpleasant dreams (Hall-Smith et al., 1997, Richman, 2000). Patients suffer with anxiety, exhaustion and loss of temporo-spatial orientation as well as the lack of communication causing insecurity and isolation (Benzer et al., 1983). Meaning was seen as important for patients to adjust psychologically (Grossman et al., 2000); however, the loss of time (memory), contribute to the meaninglessness of the experience, indeed the more severe the illness the less patients remember (Turner et al, 1990), contributing to dissociative disorders such as Acute Stress Disorder and Post Traumatic Stress Disorder (Jones et al., 2001), which are associated with ideas of suffering (Wilkinson, 2005). On the other hand, speechlessness itself has been seen to lead to anger and resignation (Hall-Lord et al, 1993), with anxiety, fear and the inability to talk being the most dominant discomfort experienced by ICU patients. Patients who were unconscious on admission reported fewer emotional problems than conscious patients (Bergbom-Engberg & Haljamäe, 1988; Perrins et al., 1998), with painful memories of the experience lasting up to four years later, emphasising the longer-term scale of the problem among those

that survive the ICU. Within the intensive care unit this made recruitment of patients, and detailing the accounts of patients, difficult. However one of the ways that these difficulties were overcome, was through the way in which consent to be a part of the research was performed, which is the subject of the next section.

The study was conducted in accordance with British Sociological Association (1997) guidelines for social science research, and in line with the Nursing and Midwifery Council Code of Professional Conduct (2002). The relevant ethical codes were invoked to guide the research process. Gaining access was not a particular issue as an employee of the NHS, but became more difficult when based within a University School of Sociology, which is focussed upon in the following chapter. In order to access the study population, it was necessary to discuss the project with the Chief Consultant of critical care services. Indeed, as part of the Local Research Ethics Committee (LREC) process, the Chief Consultant's signature was required before the application could go any further. In order to receive the director's signature, it was necessary to deliver presentations to senior medical staff within the ICU. This was secured in the first application, but the second application is the subject of the following chapter. These presentations not only provided me with 'acceptance' by the ICU consultants, certainly a less daunting experience than I had anticipated, but was also useful in as much as they were, later, willing to have their ward rounds tape recorded. I also approached the Clinical Nurse Leader for her approval, as she represented the interests of the nurses and the non-clinical management of intensive care. Due to their proximity with patients and my own experience of being a nurse in intensive care nurses figure highly in the research. The question of vicarious liability (legal protection), was also made available to me as a researcher. Thus, the organisational, gate-keeping boundaries had been surmounted. The research was approved by the Hospital Research Committee (02/aic/1551 and 03/aic/1854), which was approved rapidly for the pilot and the research proper and the LREC (02/435 and 05/wse03/02). The first LREC approval was very quick, but the second application was approved significantly less quickly, as will be demonstrated in the following chapter. This may be hardly surprising when performed among such vulnerable people as the patients of an ICU (Moore & Miller, 1999). So the next section focuses more on the process of gaining consent to be a part of the ethnography.

Considering Consent: process and outcome.

In conducting ethnographic research, particularly among vulnerable populations such as within intensive care, the ethical components of the study should be the core of the research (Johnson, 1992; Moore & Millar, 1999; Celnick, 2000). Ethical principles and concepts such as trust, deception, beneficence, non-maleficence, autonomy and justice (Beck, 1990), whilst significant are certainly not all that ethically guided research is about. These principles can be contradictory; they can be used to legitimate certain actions, which may have at their root a more dubious ethical position, an issue that is discussed in Chapter Eight. Through the use of such ethical principles, certain actions can at once conceal and reveal (Heidegger, 1993), an issue that is discussed in the following section of this chapter. The route I took and felt was the most appropriate given the nature of intensive care was one of partnership, and this was facilitated through the consent process.

The process of identifying those patients who would be eligible to become a part of the research involved discussion with the consultant on duty in the first instance. On account of having three ward rounds (one for each part of the combined Critical Care Unit), the most appropriate place to receive details of all the patients was in the morning 'hand over', before the ward rounds were split into three. This occurred every morning at ten, so for the first two weeks, I sat through this along with the nurse in charge, the consultant taking over and the day's new batch of senior registrars and junior doctors. From here, I had an idea of which part of the unit would hold the most appropriate patients and so followed the ward round on that side of intensive care. Occasionally, there would be appropriate patients for inclusion on both sides, A and B, so I decided on the most appropriate ward round to follow from the accounts given in hand over. Having already performed field work I got to know some of the patients, so had a good idea of which Ward Round to follow. I approached the consultant responsible for their respective side of the unit (one consultant took responsibility for the whole floor at night) and asked whether they thought the patient would be appropriate to be approached about the research. The consultants, who became aware of the research through either the research group meetings or seeing me on intensive care, did not see any reason why any of 'their patients' should not be a part of the research. The next port of call was the nurses, beginning with the nurse in charge of

the whole floor, then those in charge of the relevant side and finally the nurse allocated to the patient.

The nurse in overall charge of Critical Care for each shift provided a valuable insight into which patients would be the most appropriate. Unlike the consultants, who suggested that every patient could be enrolled, the nurses in charge were more careful when considering the appropriateness of inclusion. They knew the patients well, but also had a good idea of which families were having a 'tough time' emotionally and who would be best avoided. This helped enormously when it came to speaking to families or patients as those who were too stressed out by the whole process could be avoided. The nurses in charge of each area however didn't really have a problem with enrolling any of the patients although some of them, like the nurses in charge of the whole unit, gave pointers on who it would be wise to avoid. This often would be detailed to me whilst we followed the Ward Round. The nurses at the bed space, whilst in theory having the greatest knowledge of all about the individual patients, owing to their almost continual close proximity to patients (as will be made clearer in Chapter Seven) generally accepted my intrusion into 'their' space. They also acted as witnesses when patients were able to consent to the research by nodding, but were too weak to sign the consent forms. During the pilot study, one of the clinical research staff would regularly print out one of the sheets used for clinical trials detailing the pathology and treatments of all of the patients in the ICU. Knowing the exclusion criteria for the study, she would highlight those patients that she deemed eligible to enter the study. This unfortunately was not a privilege extended to me during the second period of fieldwork, not because of the lack of patients (which there was), or lack of support from the intensive care staff (who were extremely supportive), but because there were no clinical trials at the time.

Proxy consent (or assent as the research Ethics Committee demanded it to be written), to observe specific patients who were unconscious, or too sick to communicate, on admission to the ICU, was gained from those close relatives whom the staff caring for them believed appropriate to approach. The same process was involved when patients were admitted whilst I was away from the field. Although proxy consent has no legal standing in its own right (Dimond, 1990), it was performed within the spirit of acting in the patient's 'best interests'. Without this form of consent, the research could not

have occurred at all. I approached family members and asked if they believed the patient would ordinarily be a part of research such as this, that is, if they were able to communicate with me, do they think that the patient would provide consent? Information sheets were provided for the family members to look through, and they were invited to discuss the matter with me the following day, should the patient meet the inclusion criteria (see Appendix Two and Three) and provide proxy consent, or in health care parlance, assent. Summarised information sheets and a full information sheet with retrospective consent form (example consent form in Appendix Two), were left with the families and in the bed area, should the patient require it. This not only allowed the patients to read about the study but also, in conjunction with my discussions with numerous nurses, allowed them to read up on exactly what it was that I was doing there. The first LREC approval also required the patient's General Practitioner (GP) to be informed of inclusion in the study, however, to do so would be a breach of confidentiality under the 1998 Data Protection Act, therefore consent was also required to inform the GP. None of the patients thought it appropriate to inform the GP, so no information was passed to them and the second approval required no information to be passes to the GP.

Having received informed assent to perform the research, retrospective informed consent to continue observation and for interviews were gained from those patients whose families had previously given assent. This was sought as soon as practicably possible after the patient had regained consciousness, either within intensive care or within high dependency. Attaining both the formal informed consent and the assent were treated as part of a broader consensual process. This process of securing assent also meant that patients who would wish to be involved in the research but who were unable to provide consent at the outset could have their wishes denied by family members. Those patients who may wish to be a part of the study, but their families did not think it appropriate to take part would not be enrolled into the research. Interestingly, by the final encounter with the LREC panel, they argued about the right of families to deny inclusion to the research, a position counter to that of the years my supervisors and I experienced in trying to secure approval in the first place.

I opted to undertake a form of process consent and assent as well as formal consent as an outcome. This meant that with each new encounter or family member, verbal assurance was sought in order to emphasise that their implied consent to continue with the study still stood (Usher & Arther, 1998). This was felt to be sound because the family or patient would be invited to discontinue being a part of the study at any time. This formed part of the research process (Munhall, 2001), enabling those involved to become well aware of my role (Kidd, 1992), and as Seymour (2001) found, helped develop rapport with the families and the patients themselves. Thus the process allowed the participants to voice their opinion at any time, and give further ethical credence to the performance of the research. The rapport that developed between the nurses, families, patients and myself certainly helped in the accounts that derived from the ethnography, even though follow up interviews were not secured.

Whilst it is of great importance to obtain consent from the patient, it was similarly necessary to obtain approval, and hence implied consent (Young, 1994), from the nursing and medical staff involved in caring for the patient. As the patient, and to some extent their family, are protected in accordance with the guidelines from the LREC, those performing their day-to-day work have similar rights to privacy. A great deal of time and effort was spent discussing the nature of the research with such staff on a one-to-one basis, within their native environment, not only to inform them but also to develop implied consent. A common phrase being, “would you mind if I sat here for a while”, after informing the staff of the nature of the research, if ‘their’ patient had been enrolled in the study (the issue of whose patient is whose re-emerges within Chapter Six). This led a number of staff to become unofficially, and somewhat superficially involved in the ‘recruitment’ of eligible patients. As my field notes from the first period of field-work testify:

Wandering from bed area to bed area, I explain to the nurses at the bedside what it is that I am doing. I feel that being seen in a non-clinical capacity by as many of the staff as possible would help them feel more comfortable with my presence as an observer. Reaching bed 4 in the unit, I explained to the staff nurse in some detail, as I had for each other nurse at each bedside, what I was doing, he found it quite interesting, willing to ‘chat’ about his experience. I later walked back through the unit, and he called out “Paul mate, I’ve got some ‘monitor-watchers’ for you here mate”. That is, family members who spend their time watching the monitor screen, supposedly ignoring the body in the bed.

(From field notes)

Whilst explaining to the nurses the nature of the research, I mentioned examples of what it was I intended to investigate. One of these referred to family members who are transfixed by the technologies around them and as a result became a new name of a type of 'family member' for the nurse in this example to categorise. With this issue of developing a rapport with people within the intensive care unit, the ideas of reflexivity within the research are important, epistemologically and ontologically to what I was trying to accomplish through the research. As a consequence of seeking approval to perform the research an auto-ethnographic account of the ethical aspect of the research is outlined in the following chapter. The background to the auto-ethnographic research along with this notion of performing research reflexively will be presented in the next section.

On doing reflexivity and the performance of auto-ethnography.

'...reflexivity is a deconstructive exercise for locating the intersections of author, other, text, and world, and for penetrating the representational exercise...'

(Macbeth, 2001; p35)

It is through the performance of a reflexive approach that the voice of the researcher, demonstrates how a certain 'self consciousness' about the research can be put into analytic use within the context of the performance of research (Aamodt, 1991). The voice of the researcher and the voices of those researched are made distinct; no one voice is superior to the other, they co-represent the lived reality of the area under investigation. Through collaborative discourse and member validation the representational dominance of the researcher is challenged, those under investigation have equal access to voice their opinion and have the power to veto unrepresentative text through validation, lessening the hegemonic effects of positivistic social inquiry (Street, 1992; Silverman, 2000). Whereas traditional methods may perpetuate and legitimate forms of cultural oppression, collaborative discourse locates and dissects them, exposing the contradictions of research performance and organisational practice (Street, 1992). A relationship is not only built up between the data and the researcher (Atkinson & Coffey, 1995), but between the participant and researcher who are able to co-produce the text, thereby representing the lived reality of those researched honestly and with sincerity.

The reflexive inquiry takes on three main forms, the ethnomethodological (May, 1999; Slack, 2000; May, 2000), the positional (Macbeth, 2001) and the textual (Denzin, 2001; Macbeth, 2001). The positionally reflexive frame maintains that the researcher holds a certain awareness of self, is able to comprehend the effect that they have within the situation, a perspective both in terms of the researchers ontology and in relation to the impact that the viewer has on that which is viewed (Law, 2004). By recognising the potential effect the researcher has over the research encounter and being able to recognise this, creates a context from which the research can be understood in relation to these issues. Far from ignoring the effect of the researcher it is highlighted and incorporated within the research design, to the extent that the researcher themselves are part of the subject of the investigation, as for example in auto-ethnography (Spry, 2001). Those aspects of being a researcher become a central part of the investigation. The ontology, sense of history, prejudices and agenda's of the researcher are laid bare, open to as close a scrutiny as the subject under study. The way a situation is read by the researcher is accounted for, thereby settling one aspect of the research scene and illuminating it, an aspect that is more often than not concealed. As Gouldner (1971) argues, the sociologist is also part of the social world in which they are researching and even though certain techniques are used to distance the researcher, they introduce further issues to the research as in many cases a legitimisation of an unspoken ontology is obscured through a 'value neutral' epistemology. It is through such self consciousness that a greater clarity is achieved over the research as a whole.

Textual reflexivity aims to partially reconstitute the disembodied text of third person authorship. For Woolgar (1988), a continual interrogation of the 'strangeness' of the text is necessary as a means through which some of the underlying assumptions can be laid bare. Indeed, poetics, autoethnographies and cinematic re-representations (Denzin, 2001; Spry, 2001) produce texts, whilst other media, such as video are more closely held to represent the subject of the research. In contrast a positional reflexivity engages more closely with the subject matter, in part as a recognition of the effects of the epistemological position. The research is bounded by the contingencies of language, memory and the sensory limits of human capabilities (Berger & Luckmann, 1967; Gardner, 2001), it is further bounded by the representation of thoughts, feelings, as well as a sense of self (Goffman, 1959; Giddens, 1991). The

representation of such all-encompassing aspects of the research in textual form, in common with elements of mysticism and Eastern philosophical thought has been considered as virtually impossible (Bohm & Weber, 1981) leading to an incoherence; a mess (Law, 2004). However, through new textual forms such as poetics and auto-ethnography, it is possible to represent aspects of the investigation reflexively. The problem of textual reflexivity revolves around the accurate portrayal of the research outside of the contingencies of traditional pseudo-scientific third party, disembodied social science writings.

A collaborative approach to reflexive research as adopted by Street (1992) in her ethnography of clinical nursing practice focussed on the dialogic connection between the researcher and the co-participants. This produced a piece of research that, far from being performed 'on' people, relied on their co-operation to be performed 'with'. This allowed the free exchange of information, and to some extent part ownership of the research. The research act becomes a force for change, an opportunity for participants to reflect on their own situation, and in some cases develop an understanding of oppressive power structures and their effect on themselves (Street, 1992; Denzin, 2001). A reflexive social science belongs to a moral community, the community who co-produced it, the researcher and the participants (Denzin, 2001). It turns the narrative of the ethnographic data into a political act, empowering the co-participants to imagine a social context free of prejudice and power constraints (Denzin, 2001). Other reflexive approaches research, such as Anderson's (1991) fieldwork within the organisational context of health and hospital work take a differing reflexive stance. The dialogic encounter is one of reciprocity; in Anderson's (1991) research the fieldworker needed information concerning the experience of illness, whereas the participant required information concerning their health status. Thereby both parties had a reason to perform the research, and both benefited as a result. Perhaps a relationship built upon trust and mutuality can not only be beneficial to the parties concerned, but produce research which does not deny its bias and represents its findings in a manner which is true to the experience of those investigated, and the cultural context within which they arise through respondent validation. The empirical chapters have been reviewed by 'members' in the field, some of whom added comments, to justify a certain position or observation.

For the most part, this engagement was not possible with intensive care patients on account of the speechlessness that is a consequence of mechanical ventilation. Whilst I spent time with those patients and families within intensive care, it was a rare opportunity to speak with them afterwards. When this was possible, most of the interviews were in the form of conversations about things that patients and family members were concerned about. Jean and Lilly shared apprehension about being transferred to the High Dependency Unit, where they wouldn't find a nurse at the foot of the bed. Jean expressed concerns about never being able to speak again, whilst many intensive care patients experienced frustration and anger about being within intensive care and their speechlessness in particular. For the most part, I sat, stood or leaned and listened to what they had to say, about how some of the staff were just rude, about who was going to feed the cat and when I could offer help and advice about intensive care in particular I spent time explaining the procedures and routines of intensive care. Without being able to change the structure and organisation of intensive care, or their place within it, an attempt was made to provide a context from which their experience was located and perhaps true to form for a former intensive care nurse, make the unfamiliar familiar, the abnormal normal, perhaps upending the traditional fieldwork approach of making the familiar strange in making such strangeness familiar and tangible. In this way, whilst not a grand means of moving away from the legitimisation of oppressive power structures, it is through small individual actions (Rapport, 1997) within a research context that make being critically ill and the consequences of it more bearable and in this small way I hope to have achieved this. However, it is not without its dangers as will be presented in relation to Dottie and Lilly, two patients who agreed to be a part of this ethnography.

The so-called crisis of legitimation and representation (Lyotard, 1986; Denzin, 1997) arose out of wider social and cultural attitudes, emphasising disillusionment with the meta-narrative of a 'modern' cultural order. The postmodern reading of such research has led to a reconfiguration of what counts for legitimate, how it is made so, and how the legitimate discourse is represented, both within academia and society at large. As a means of addressing some of these problems, social scientists developed means through which research recognises the problem of legitimacy and representation through a reflexive epistemology. However, owing to the problems of gaining interviews, particularly follow up interviews, this level of textual praxis was never

fully realised within this thesis. The ethnographic accounts that involved the critically ill came from a point of observation and interaction, however, the contingencies of intensive care made it impossible to talk with many intensive care patients. As patients were lost to the study it was not possible to relay the text back to the participants, which of course leads to a further problem of textual reflexivity. On the other hand these aspects of performing research were seen as something to strive toward informing my theoretical position, even if not fully realised in the practice of this research.

‘As a form of textual analysis and as an orientation to textual production, *autoethnography* renames a familiar story of divided selves longing for a sense of place and stability in the fragments and discontinuities of modernity...’

(Neuman, 1996, p. 173-174).

From the outset there was seen to be no reason to perform an auto-ethnography. Producing an auto-ethnographic account was incidental to the problems of gaining approval from the Local Research Ethics Committee; which became such a key issue to the research. But this was not necessarily serendipitous, although if we followed Merton and Barber (2004) even serendipity itself is not necessarily graced with serendipity. And so, like those non-serendipitous discoveries before it this non-serendipitous, serendipitous discovery of the centrality of the LREC to this thesis was born, found by chance as will be demonstrated in the following chapter’s account of gaining approval. So to some extent in this instance positioning theoretically a performance of an auto-ethnography comes ‘after the fact’, it was not intentional as part of the original research design. Yet there are very good ethical and theoretical reasons for performing an auto-ethnography and these reasons were part of the theoretical foundation on which the original research is based.

The foundation was concerned with sound ethical reasoning as the basis for investigating those who are critically ill and are completely reliant upon the work of strangers for their survival. It could similarly be argued that any interpretation of data comes after the data has been produced, *a posteriori*, so perhaps similarly when presenting and representing a particular method then the discussion surrounding the reasoning for any particular social science method should come after the fact as the world which is under investigation is not static, changes are made to the way that research is performed given the contingencies of the changing social world under

investigation. A particular desire to perform a particular type of research necessitates a particular method that may well be altered given the contingencies of the field. But for the most part a particular epistemological and by implication ontological allegiance is made which determines the shape of the research and in turn its method, from the outset.

Unlike Neumann (1996), performing auto-ethnography in this instance has little to do with a divided self, whatever that might be, or longing for a sense of place, or stability in an unstable world. It is not order, as such, that is sought, though auto-ethnography like many textual representations impose order (in Neumann's sense) on something that is not necessarily ordered or orderable, to enable sense to be made of a given situation or culture. Whilst as an individual therapeutic exercise this may be helpful, it is not the intention, nor would or should it be, at least in this instance. The old order, which when re-presenting 'order' it necessarily will be (Derrida, 1976) given that ordering work in producing text is in part restructured and abstracted (Ong, 1988), are continually discarded re-envisioned and partial (Strathern, 2004). On one hand representations of order reveal and by implication conceal (Heidegger, 1993) those aspects omitted through representation. Through giving an *account* and in this instance an auto-ethnographic account, a context can be provided from which to understand a cultural artefact (Munro, 1999) and in the following chapter, the cultural artefact is in part represented through the ordering work required to gain ethical approval. By this it is meant that (partially) through the auto-ethnographic account some steps toward understanding the significance of what organisational systems such as the LREC accomplish can be made. In this case it is from the perspective of the materials in the form of correspondence that the LREC is made visible and through face-to-face encounters. In part it is these accomplishments, albeit seen through a particular lens that can give telling insights into what it is that constitute an LREC, how it orders and how it is in itself ordered. But this lens constructs what it makes visible, it is through visualising the LREC from a particular position, and in this sense a position of a research student that the LREC that enables a co-creation of meaning of the accomplishments of the LREC. From such a perspective, the accomplishments are seen in relation to the ethnography as a whole and from the perspectives of the LREC panel members as made visible in meetings with them.

In the opening paragraph I alluded to doing a particular type of research that was ethically grounded. Initially, I felt that the separation of issues surrounding ontology and epistemology would be deeply problematic, at least theoretically. In its crudest sense separating the two seemed like a sort of ‘do as I say and not as I do’ relationship between a theoretical position and the performance of ethnographic research. Having philosophical beliefs that did not match the way that the research was envisaged and conducted seemed a little dishonest. It suggests that an individual research method is used to investigate a given situation because it is ‘the best tool for the job’. This, on the face of it, seems quite reasonable; why not use a research method that purports to be the most appropriate tool for the job? Indeed it seems quite right on one level to choose a particular method that is best suited to the task at hand, and in some respects I would go along with that. The danger for me was that research methods themselves are not value free; there are some implicit assumptions being made at the point in which the research method is developed and planned for the research task. As such, it becomes very difficult to produce a form of research that is value free (if such a thing ever has or ever could exist) and it is these values that come to muddy the way that empirical research is conducted. Certainly as a practicing intensive care nurse at that time it was important that research was conducted in a way which did not efface or run counter to being on the one hand a ‘trainee’ researcher and simultaneously a registered nurse with so many years of training and experience. Certainly as part of the study, there were times when it was necessary to step back from my role as researcher.

I had been visiting Lilly (Bed 10 in Appendix Four) almost every day for about ten days when her sister came to Wales from England to visit her. Lilly was being mechanically ventilated through her tracheostomy tube and as such was unable to speak, she was critically ill but she was no longer anaesthetised so was able to mouth words to health care staff and family members. On this particular afternoon, her sister was talking about her life and telling her that she would be out of hospital soon enough, but Lilly was trying to tell her something. Each time she tried to speak to her sister, who was unable to read her lips, her sister started trying to guess what she was trying to say which made Lilly increasingly frustrated. After numerous ill-fated attempts at randomly guessing what was being said, Lilly turned around and swung her fist at her sister’s face. The ventilator alarmed and the nurse came over from the

desk at the foot of the bed, spoke to Lilly, silenced the ventilator alarm and led Lilly's sister to a chair for a sit down. As I had spent so much time with Lilly and had become so familiar to her she explained that she had just had enough and why didn't her sister just listen. The nurse asked her sister to leave for a 'few minutes' and should ring the bell to come back in, meanwhile Lilly burst into tears. I sat down with her for about ten minutes and explained that such frustration was a normal reaction and that many patients in intensive care feel similarly. She seemed to perk up a bit, her sister came back a little while later and they just sat there together, silently.

Now on the one hand it would be seen as perfectly acceptable behaviour to remain a passive observer, just witnessing what happens, when almost inevitably, the intensive care patient, in this instance Lilly, becomes frustrated and angry. On the other hand as a nurse (or even a compassionate individual) there is an obligation to do something positive in the situation, even if that does not constitute a great deal in itself. The concern, on the one hand, is that the data collected can be tarnished; perhaps the nurse as researcher cannot let go of those old traits bound up with professional identity (Morse & Lipson, 1991; Kite, 1999). On the other hand it could be seen as a form of praxis, whereby unlike Lather (1986) the idea is not an educational route to emancipation through research, or literacy (Friere, 1990), but in the skills I held to help those who are critically ill. To perform this type of research, a recognition that some fluidity would need to be in place as part of the research, so as to prevent the research having an adverse effect on the research population and recognising the contingencies of an environment characterised by (among other things) human traumas. So through praxis, there is recognition of the duality of ontology and epistemology as well as the place of the individual researcher (Rapport, 1990) as part of the research process. This requires some degree of openness, of vulnerability on the part of the researcher (Denzin, 1997) on account of elaborating on the production of the research, its motivations and the rationale for a particular form of representation. This to me is far more crucial to praxis as a means through which those implicit values and judgements held about research are made explicit. To this end, whilst not a serendipitous emergence into auto-ethnography, auto-ethnography in itself is wholly compatible with the research as praxis.

Performing such participatory reflexivity within the ethnography also has its down side. As result of a policy of informing the staff of intensive care of the nature of the research I gave a number of presentations to nursing and medical staff, as well as placing a large poster detailing the nature of the study outside the Sister's office on the 'A' side of intensive care. This was done to familiarise the staff of the ICU with my role of ethnographer. The degree to which this was achieved can be partially accounted for in being called over to assist one of the staff nurses and an undergraduate student to communicate with Dottie:

As I walked over to the bed area, she looked over to me. I had previously explained who I was to her and her family within the process of attaining consent. Neville (the Staff Nurse) and the student were now stood by the bedside, Neville was getting quite frustrated whilst the student was just watching Dottie's hands. I walked from the foot of the bed to Dottie, Neville and the student went to the foot of the bed and started writing down the observations, as Dottie had a new minder, me. I explained to Dottie who I was and what I was doing there, she moved her arms and mouthed something I couldn't make out. I asked her to talk slowly, and exaggerate her words with her lips. She tried again and still I failed to understand. I thought I understood some of it, so I asked "is it something you're feeling?" She nodded her head, and said something like "pass me my glasses." I looked but couldn't find them, they had apparently gone home with her belongings, a common practice within intensive care as the hospital is unwilling to take responsibility for loss or damage to personal property. Her husband had said to me earlier "she doesn't really need all this stuff here, does she?" I told her that her husband had her glasses, and that he would be in to visit in the morning. She mouthed "back", so I asked if she would like to have the bed positioned back. She mouthed "yes", so I used the electronic controls to lower the top of the bed. As I was doing this, she grabbed the catheter mount connecting the ventilator to her tracheostomy, and pulled it off, but she refused to have it replaced. I held her hand, stroking it gently and replaced the tube whilst she was more settled. Neville was grinning at the foot of the bed, writing down the 'obs' unperturbed by Dottie's actions. Dottie closed her eyes, opening them only when the bangs, scrapes and chatting of the nurses interrupted her. Neville and his student continued talking, nothing out of the ordinary was happening as far as they were concerned.

(From field notes)

Through performing research with a vulnerable population it was felt that a certain micro-interactionist (Kosmaroff, 1995) ethics be conducted in addition to the formalised rule and accountability ethics of the formal LREC. A positional reflexivity regarding the relations between the epistemology and ontology was produced and that between the researcher and the research site. To some extent a form of textual reflexivity through auto-ethnography was also conducted, albeit as an unintended consequence but before this the emphasis was about the voice of persons participating in the research and the voice of the researcher should be made explicit. Given the problems of 'losing' research participants for follow up and the issue of speechlessness made this more difficult within intensive care.

Through recourse to the two intensive care patients, Lilly and Dottie two countervailing issues concerning a performative reflexivity emerged. On the one hand this approach aimed to assist Lilly with the frustrations of being speechless within intensive care. I regularly spoke to her about her cats at home, about playing cards and for the most part I was simply a 'friendly ear', or at least that was the intention. On the other hand, attempting something similar with Dottie resulted in her succeeding in extubating herself. My familiarity with the nursing staff meant that they were happy for me to be sitting with her as it meant they could perform other duties around her (issues concerning Dottie reappear in Chapter Eight). Nevertheless, this put Dottie and myself in a difficult position, for Dottie this was a position of risk of damage as a result of the action and for me the ethical problems of perhaps leading to adverse physical-medical consequences as a result of my intervention. For the most part though, I believe that my position was not ethically flawed, the nurses were always present, but the question remains as to whether this was an appropriate position to take in practice as opposed to the more lofty theoretical call to performance. It is a question of doing the right things for the right reasons, but they may have negative and unforeseen consequences as a result.

On Method.

This ethnographic research of an intensive care unit has been based upon multiple methods. Interviews were conducted with numerous staff members that worked in intensive care, nurses, doctors, reception staff, psychology and counselling staff, technicians as well staff in educational roles either attached to intensive care itself, or teaching intensive care in the local universities. Patients' and family members were also interviewed at different points during their stay in intensive care and when possible, following discharge. Documents, such as local policies, national policies and government reports were analysed and informed the analysis of the data. Recordings were also made of key oral processes within intensive care, the Ward Round and the Hand Over periods (both the medical and nursing handover) in addition to certain meetings. Both the interviews and recordings were transcribed using loose Jeffersonian (Sacks, *et al.*, 1974) conventions, analysed textually by the constant comparative method (Glaser and Strauss, 1967), across cases and across time. For the most part the fieldwork was based specifically within the confines of the intensive

care unit. However, when the opportunity arose I followed intensive care staff to other hospital intensive care units both within the city and within neighbouring towns and cities, when patients' were being transferred in or out of intensive care.

The pattern of conducting fieldwork altered over time with continued exposure to the site. The fieldwork began with presentations to the intensive care research team (mostly senior nurses and consultants) in order for them to be made familiar with what I was doing and why. On each day of fieldwork, the nurse in charge was approached, and I discussed the research with them in the office before going out into the clinical area. Here I walked from bed space to bed space discussing the research with individual nurses who provided an insight into patients that would be appropriate to enrol into the study, and therefore be amenable to follow through intensive care and onto discharge. The Ward Round provided a similar opportunity to follow the consultant and senior nurse around intensive care. The senior intensive care doctor had agreed to the ward round being recorded which set a precedent whereby it became more difficult for subsequent consultants to refuse to have the ward round recorded, indeed one consultant reminded me to place the recorder at the foot of the bed, further cementing the place of the recording instrument on the Ward Round. Patients who were seen by intensive care staff as appropriate to be enrolled in the study were followed through to discharge, where possible. This meant that the fieldwork was able to be concentrated within a particular space, the patient's bed area, which ensured only those patients enrolled in the study were part of the data collection, yet the rest of intensive care was made visible from their location. The consent process allowed me access to patients and families and provided an opportunity to get to know more about the unconscious patient through conversations with family members. Key to this was the building of relationships with patients, family members, friends and the intensive care staff as a whole.

Details of the routine practices of a day within intensive care were written up continuously (and more legibly at home). For the most part the staff of intensive care were familiar with me writing on either the central desk, in the office or at the bedside. Some asked what I was writing, taking an interest in both what I could be writing about them as well as the research, I always showed them what I was writing and when necessary explained what I was doing and took the opportunity to explain

what ethnographic research was about (they could see these things anyway). Writing ethnography in open view became an occasion for the staff to engage with me about their work and about their experiences. It was more practical than say the coffee room where I spent my time talking and being interrupted. Importantly though, the coffee room became a site where I was given access to the gossip of the intensive care unit, issues emerging, bickering and tales of intensive care. I was also called upon to take food with the staff (particularly breakfast and supper), following a small group of nurses generally to the hospital canteen. For some staff however, my presence was slightly strained yet always couched in humour, and provided a right of reply to the staff involved. This right of reply was figured as part of the analysis where some of the intensive care staff were invited to read over drafts of the research and make comments upon it as to whether they felt I had accurately portrayed intensive care or their part in the ethnography. However, the ethnography has been written up in relation to certain events, or a period of time with certain patients, so for the most part is not visible within the thesis, yet was central to its representation. Owing to difficulties with maintaining contacts following discharge, such an opportunity was not open to me with patients and their families.

So the way in which the research has been represented in this thesis is a very small proportion of the data collected. Family members were a great source of information about patients and at times my role became that of mediator between 'family members' and speechless intensive care patients. On account of the speechlessness, I assisted with lip-reading on the behalf of patients; the nurses themselves were able to perform other duties whilst I did this so it became an accepted and acceptable way for me to perform fieldwork, being helpful whilst not getting in the way of the work of intensive care staff. As noted in the previous section of this chapter, this was felt to be of great importance, that I was able to provide something positive to those people kind enough to allow me into their personal and working lives. However, the fieldwork within intensive care was only one part of the research. For numerous reasons, ethics became a central concern and is reproduced within the following chapter (Chapter Five), and rests upon two panel meetings with the Local Research Ethics Committee and correspondence between myself and the committee which spanned four years.

What Next?

This chapter has aimed to demonstrate some key features of the research. A background to getting into the field has been presented along with some of the problems of performing research within intensive care more generally. These problems were addressed in relation to the research as a particular process. Aspects of treatment within intensive care, such as mechanical ventilation as well as the physical and emotional consequences of surviving intensive care were drawn upon in order to demonstrate how these issues were dealt with as part of the research process. The intention was to negate some of the problems of performing intensive care before they arose, but a problem of securing ethical approval, as is demonstrated in the following chapter, proved a far greater problem than was originally anticipated. The means through which consent and assent were both process and outcome was felt to be a particular strength of the ethical conduct of the research. I believe this still holds as an important part of the research process.

A key aspect of the research is its engagement with the idea of reflexivity and that has been discussed in the previous section of this chapter. Positional reflexivity was introduced as a theoretical engagement and ties in with Chapter Two. But it is also read in relation to proximity, between the researcher and the research participants. Ideas of alterity, between the subject of the research and the researcher are made more explicit, particularly with regard to the auto-ethnography (Chapter Five), which in turn invokes the researcher as subject. These auto-ethnographic accounts also emerge in other places, such as in Chapter Two (briefly), when entering the field and in relation to performing consent (in this chapter). It is through this representation as a textual form, which is referring back to the positional both theoretical and relational that this idea of reflexivity takes its significance. The danger in trying to get away from this alterity, of otherness between self and subject that is embedded within the process of writing ethnographically (Clifford & Marcus, 1986). The danger is of creating an incoherent 'mess' (Law, 2004). The aim is to emphasise those unequal power relations within the research (Denzin, 1997, 2001), whilst also allowing some flow of the narrative(s), rendering it legible. This led to a performative reflexivity, invoked as a means through which the researcher can put something positive back into the 'community' that was researched through which the potential for quite

negative effects. The proximity and the refusal to perform research at a distance, as a non-contributory fly on the wall, but to actively engage in the social (Denzin, 2001) did have some consequences, as noted in the previous section. But as will become clear in the subsequent chapters, this also allowed a certain depth of the ethnography to which a passive observer may not necessarily be able to engage with so readily.

The opening section of this thesis (Chapter One) provided a context for the research. It highlighted those intended aspects of the research that informed this thesis but never made it to fruition remain as a feature of this thesis through extension. From the point of the supplement (Derrida, 1976), the second chapter provided an insight into the theoretical underpinnings of the research, which tie in with an overall theoretical position, which inform the conduct of the research. This gave rise to an exploration of intensive care as a cultural performance, a trope to things that may not be the physical place of intensive care but of intensive care as a real-and-imagined space (Soja, 1996). It is viewed as a space of invocation, of feelings and of emotions (Bachelard, 1994) that has a cultural resonance beyond the confines of a localised place. This will lead in the following chapters to an analysis of the intensive care unit as a multiplicity of spaces, of spaces that are contested, spaces that invoke emotion, spaces that separate and make other. This will be described in relation to the people who inhabit intensive care, the patients, the families and the staff members. However, before that an account of the process of securing ethical approval will be made in the following chapter, a space that I personally found problematic. This in part is reflected in a slight change of tone with a small amount of *post hoc* analysis that interposed the narrative, it does come under scrutiny but for the most part Chapter Five is a roughly sanitised reconstruction of notes taken from the field notes, field diary and correspondence.



Chapter Five.
On Not Performing Ethnography.

Introduction.

The following account represents the first 'empirical' chapter of the thesis. It is in part an auto-ethnographic account of my experience of gaining ethical approval and some of my motivations for performing the research. Laid out as it is as a unitary narrative, it obscures issues in collecting the data through its presentation, as some aspects came from field notes, the research diary, some from official documentation and correspondence with official agencies whilst some are from talking through 'what actually happened' with others such as my supervisors. As such, in some ways, it could be viewed as a non-empirical account with respect to the multitude of sources from which it derives. On the other hand, this is in part how human experience is shaped (from multiple sources) which are not readily discernible to a concrete moment. As has been made explicit elsewhere (e.g. Clifford & Marcus, 1986) the visibility and perspective of the researcher is tied in with the representation of ethnography and autobiography. Inset among this representation sit two interjections. These have been placed there as they become increasingly central to the major themes in the research; the down side of course is it reflects slightly in the flow of the narrative, whilst revealing that these were added to the text, applied and reflect a supplement to it (Derrida, 1976).

When constructed these accounts become temporally located and specific to the time in which they were written (Denzin, 1997), or contemporised (Derrida, 2001). Through taking a critical distance from the event through time and place, in this case having completed the fieldwork and being situated in an office away from the field site and then re-constructing it with others involved in the ethical application, then the representation of the data alters. Those particular 'prejudicial' insights which allow field data to be collected and allow free passage through the field have become a part of history. Or at least a part of the history of this thesis and as such are evoked as means of understanding and one that is not coloured by some quite harsh feelings that

came with the process of gaining ethical approval (as will be made clear within this chapter).

Part of the seduction of an auto-ethnographic account is its blatant challenge to certain ideas of representation and legitimation. That is those aspects of research which, for example from a post-colonial stance negate the voice of the other, even from its epistemological roots (Atkinson & Coffey, 1995). Spivak (1999) highlights this issue with the question of 'when does the subaltern speak' and the answer could be seen as never, as they are always (re)presented ethnographically through recourse to the ethnographer. In part this is seen as a problem of modernity as a project (Bauman, 1994), to which some aspects of the postcolonial relate. To redress the balance it has been seen as a requirement to have the voice of the other, which emphasises the role of research as a whole as a deeply political act (Murphy & Dingwall, 2001), giving equal weight to the veracity of the voice of the other. Of course, one major issue with this type of research is to what extent does it just become self-indulgence on the part of the auto-ethnographer and at what point is it a legitimate piece of empirical work. On the other hand whose other voice is being represented is of course another troubling issue (Trinh Min-Ha, 1989; Spivak, 1999). For the moment, the issue is about accounts and this particular account of gaining ethical approval, questions concerning text, their relations to any external lived reality (whatever that may look like) and separation of the factual from the fictional are at this point at least secondary considerations. More significantly, the theoretical issues associated with auto-ethnography are wholly compatible with the espoused theoretical position, from this point it is simply necessary to begin telling an empirical story.

On Seeking Approval.

Having completed a four-year undergraduate nursing degree in 1999, I secured a post as a junior staff nurse within an intensive care unit. As a student I was interested in the problems of ethics and produced an undergraduate dissertation that focussed on the notion of human suffering and its relations to health care practice. Intensive care, my tutor remarked '...is where nurses stop nursing people and instead become a slave to machines...' suggesting that I would be operating on the level of a technician as opposed to working closely with people. However, I was not so convinced and

commenced work in intensive care, completing the foundation in critical care nursing. As part of this, I submitted an essay for publication within an intensive care nursing journal (White, 2001), the focus being some of the human issues on the part of the individual nurse surrounding the performance of uncomfortable and invasive procedures on intensive care patients. I began to read more widely and found that there was very little information on how intensive care practices impacted upon the experience of survivors of intensive care. I had been invited to take up a Ph.D. studentship in the School of Nursing following graduation but felt that I was first and foremost a practitioner, however after a year in intensive care I felt that such an opportunity would allow me to continue with my clinical responsibilities whilst simultaneously investigating aspects of the lived experience of intensive care.

I discussed my project (at that time deeply phenomenological), with two professors within the school, the second, who will be referred to as Professor 'Jones', suggested I try the School of Social Sciences if I wanted a more rounded appreciation of research methods. I duly forwarded a research proposal for the study and received a telephone call from Dr. Latimer about a week later. We met and I was extremely impressed with what she had to say, in addition to her boundless enthusiasm, and within a month I had submitted an application for an Economic & Social Research Council (ESRC) studentship. Three months later I found that I had missed out on the studentship by 1% (I scored 86, the cut off was 87), at which point I felt a tad low and was not convinced that I had the talent or intellect to carry out a project that was (in my mind at the time) not worthy of funding and by implication pursuing. With the benefit of her enthusiasm I was persuaded to undertake the M.Sc. (Social Science Research Methods), and work toward gaining an ESRC studentship the following year.

Working virtually full time in intensive care, I started the full-time masters programme in October 2001. By this time I had been promoted, taking more responsibility for new staff nurses, setting up and running a journal club and working permanent night shifts in order for me to attend lectures. The research as I had designed it was devised as a rolling programme of work from the pilot study that was undertaken as part of the M.Sc. to the doctoral program proper. At this point I had resigned myself to continuing through to a part-time Ph.D., but it was suggested that I would gain more from my doctoral experience as a full-time student. The pilot study

was an ethnographic investigation of participation and interaction among speechless ICU patients receiving ventilatory support, families and intensive care staff. The investigation required close observation around an enrolled patients bed area for periods of about an hour at different times of the day or night. Four patients were followed up until discharge and interviewed about their experiences (with varying success as noted in Chapter Four).

In order to gain ethical approval for the pilot study I initially approached the nurse manager who pointed me to the Chief Consultant. The Chief Consultant asked me to present the research at one of the intensive care consultant meetings as he was interested in what the research was about. Armed with a background in things phenomenological and a new found interest in symbolic interactionism, I presented a 30-minute talk on the research project. The Chief Consultant exclaimed “bloody brilliant” after I had concluded the presentation and encouraged the consultants to ask me some questions. The first question I received was concerning the use of a new questionnaire tool that had been developed that the consultant had heard about at the European Society of Intensive Care Medicine conference earlier in the year. The Chief Consultant interjected, telling him that this was not a quantitative piece of research which you could transfer to a statistical package, this was a piece of qualitative research, going on to suggest that he hadn’t understood my talk at all. I had found my first ally. The Chief Consultant was indeed a good ally, providing signatures for the hospital Research and Development department ensuring that acceptance would be a smooth process. Indeed, the presentation meant that the consultants accepted that I could record their ward rounds on a dictaphone; it had been sanctioned by the Chief Consultant after all. The nurse manager was also quite happy for me to conduct the research, particularly as vicarious liability was assured as a National Health Service (NHS) clinician researcher, indeed she provided me with four weeks study leave to perform the research. I submitted a detailed research protocol and attendant patient and staff information sheets and consent forms to Panel A of the Local Research Ethics Committee (LREC) for ethical approval in March 2002 and with some minor amendments I received full approval by June, commencing the pilot study in July. Following the guidelines laid down through the Centre for Research Ethics Committees (COREC) the patient information sheets and research protocol were submitted, again requiring only minor alterations in order to

receive favourable ethical review, and so work on the pilot study began immediately and was completed in September, 2002.

Having been successful in being awarded an ESRC studentship for a three year PhD in August 2002, I started work on the research proper, registering with the university in October. Along with my principal supervisor we felt that gaining ethical approval would not be an issue on account of the relative ease of gaining it for the pilot. The first year of the Ph.D. should be about 'learning sociology', developing a thorough understanding of what contemporary sociology and social theory was. I also worked through and developed a strategy to perform an ethnographic piece of research which had the potential to influence policy makers involved in intensive care. During this first year I applied for a new researcher award sponsored by the Journal of Advanced Nursing and managed through the Royal College of Nursing (RCN). I submitted a précis of my research to the RCN and won a place as a delegate at their research conference, this would be my first experience of a large international conference, which I thought would be good for my development as a researcher. At the time, whilst grateful for the opportunity, I felt a little bit of an outsider looking in at a party that I shouldn't really have been invited to. After taking time to read around the subject and present papers at a school seminar and an international conference based upon material from the pilot study, I began the process of seeking ethical approval. Being based within a school of social sciences, which at that time was not linked to the medical school (College of Medicine), and therefore not having direct links to the National Health Service, the application process was far more convoluted and difficult than anticipated.

Speaking to staff at the NHS trust Research and Development (R&D) department, I found that it was first necessary to gain an NHS contract before I could submit an application to them. In short, I would be unable to perform research on subjects within the NHS unless I was a member of staff of the NHS, that is, if I received an honorary NHS research contract. As such, I approached the Chief Consultant of critical care who suggested I speak to the nurse manager of Adult Intensive Care. She pointed me toward the directorate manager who required a *curriculum vitae*, a research protocol and references from the Chief Consultant and nurse manager. A series of e-mails followed which took a month to give me any definitive statement as

to whether I would be given a contract and I ultimately completed an application form to be sent to the personnel department (after letters were sent by the Chief Consultant and nurse manager), which then took around two months to process.

By March 2003 I had received my research contract as an honorary research nurse, which entitled me to apply for internal review (by the R&D department) and on the 4th of July I had had the project risk assessed and approved by the NHS. The delay was largely due to the limit of completed applications they receive and consider each month. Twelve applications can be processed per month and have to be submitted by a particular deadline. Those that are not seen at the next meeting are then followed over which adds to the delay. Of course without their approval no further progress can be made with the study. So, this gave me access to the research site (pending approval by the LREC). By July 2003 I had received full approval by the NHS trust. Their requirements to fulfil my role as researcher were:

- a) Inform the Trust R&D Office if any external funding is awarded for this project in the future.
- b) Maintain a complete record of the number of patients/samples in this study
- c) Complete any questionnaires sent to you by the Trust R & D office regarding this project
- d) Comply fully with the Research Governance Framework for Health and Social Care in Wales and the Trust's Good Research Practice Guidelines
- e) Adhere to the protocol as approved by the Local Research Ethics Committee.

At this point, even though it had taken 9 months to get as far as this, particularly with the personnel department slowing things up by a number of months, I felt quite positive about gaining ethical approval. I was now preparing papers from the pilot study and doing some theoretical background reading. I also made links with another project based in Oxford (Database of Personal Experiences of Illness or DiPEX) and was considering using my data to help inform an intensive care based website which would allow those who have experienced intensive care or in families where someone has received such care an insight into others experiences. However, the project required the interviews to be conducted in a certain way in front of either a camera or just audio recorded. I felt that performing interviews with people in a structured way would introduce issues that some may not find relevant and had the potential to guide the interview away from the ethnographic accounts. So I opted to continue with the research in the way in which I had planned and applied for ethical approval in August 2003.

I also met with the director of the Intensive Care National Audit and Research Centre (ICNARC), which is an independent, national resource for the monitoring and evaluation of intensive care. It is affiliated with the Intensive Care Society and within UK intensive care terms, is a highly significant research centre that is well known to those who practice within intensive care. Largely, the discussion was based around what qualitative research could offer ICNARC, particularly as this was an organisation which had evaluated illness severity scoring systems and predictive models, yet had little grounding in anything to do with the experience of patients. Hence the research filled a particular gap that they had as an organisation. We discussed the possibility of a post-doctoral collaboration, as the project seemed to fill a gap in their research repertoire. The project seemed to be going in the right direction.

Part of the research aimed to examine the organisation and practice of intensive care and its relations to the experiences of patients and family members. As part of this a grounded comparative method was envisaged so that some of the insights developed from the first site could be fed back in to develop understandings from a second site so as to cross-check data from one site to the other. Having made headway with the initial site it was felt to be the right time to begin work on introducing myself to the second site. The Chief Consultant had contacts in ICUs throughout the UK and so started a process whereby I could approach the Chief Consultant of the second site, which was in a large English city and begin the process of gaining the support of these stake holders in readiness for LREC approval. However, performing research on two sites would be prohibitively expensive, I was receiving less than half the salary I was previously receiving as a nurse on an ESRC stipend and the possibility of paying rent on two residences at that time would be impossible. I approached the British Association of Critical Care Nurses (BACCN) and applied for a small research grant and budgeted for the cost of the research. I submitted a detailed proposal of what the research was about, how it would benefit the BACCN and the way in which an additional research award would benefit the project. Some time later I received a letter informing me that I had won the research award and that the condition on which the award was based would be to publish part of my research in their journal on completion of the research. By this time it seemed as though nothing could stop the progress of the research, even though no empirical research had as yet been

conducted. I focussed then on gaining ethical approval from the first site as I felt it was more important to be able to perform research in the first site in order for the research to be conducted in the second. This was a decision based on the fact that if any problems arose from ethical approval from the first, then it should be sufficiently ironed out through precedent for the second. As a fall back position, the DiPEX proposal already had Multi-Centre Research Ethics Committee approval and would mean that I could conduct the research with a preliminary evaluation from each LREC.

Perhaps one of the most difficult things about writing the approval documents in preparation for submission was finding the Chief Consultant to sign the forms. As he had recently fractured part of his spine when falling off a wall at an intensive care conference, he was difficult to track down and the Acting Chief Consultant was not much easier to find. I eventually 'collared' him after a ward round and asked him to sign the ethics form. He wanted a full and frank overview of the project as well, which I duly presented and the signature came. The project was only a little behind schedule. As far as doing the background reading was concerned the project was making headway, having now presented it to the school, the consultants and an aspect of it to an international conference as a poster. The continuation of the project was now firmly within the hands of the ethics committee.

In August 2003, I found out that the project had failed to meet ethical approval on the grounds that there was no evidence that the Chief Consultant and staff of the intensive care unit had any awareness of the research taking place in their unit. This struck me as odd given that the senior intensive care staff had expedited an honorary contract for me and were involved in drawing up the application for internal risk assessment. This may have been due to naming my supervisors as ultimately responsible for the project and I would become the principal investigator; however, this was not what was required of me (a point that will gain significance later). For resubmission I had to demonstrate that a number of things had been achieved:

1. That the intensive care staff were aware of my project and had endorsed it by providing signatures on the appropriate form. To quote from the form, '...no details had been provided for the supervising consultant responsible for the study in the Intensive Care Unit. It was difficult for the Panel to establish whether the Intensive Care Unit were aware of this study.'

The Head of the Intensive Care Unit should be aware of and endorse any study being conducted in his/her department.'

2. That an interview schedule should be attached as a separate document in addition to being completed on the application form.
3. That nurses are approached before any contact be made with any patients or family members (a point emphasised in my documentation) in addition to the shift manager and individual consultant on duty.
4. A dyssynchrony occurred between the documentation concerning exclusion criteria.
5. A GP letter was included when I had stated that GP's would not be informed of the study.
6. The patient and relative information sheets were shortened as they were deemed to be too long, the information sheet followed the guidelines as set out by the Central Office for Research Ethics Committees (COREC).
7. Bro Taf LREC had changed to South East Wales LREC and needed to be altered.
8. Version numbers and date did not appear on the research protocol.

The majority of the issues were simple administrative errors that occurred during the process of putting the application package together and were simple to rectify. The application was, after all, a simple re-jigging of the successful pilot application. However, it was becoming clear that the LREC failed to recognise the position of the Chief Consultant as the medical consultant responsible for the whole of critical care. So, for the next application, I assured that the signatures of both the Chief Consultant and the Senior Nurse Manager appeared on the covering letter in addition to the application form, adding to the previous signatories. I also altered the layout of the information sheets, which were already completed along the convention as laid out by COREC and with the assistance of the Research Nurses (who complete these forms frequently for biomedical research trials) within intensive care.

The second submission was prepared in March 2004. The points above, brought up by the previous committee, were addressed and amended in order to satisfy their criteria for ethical approval. However, getting all parties to sign the same form took time and so the revised form was submitted in June 2004. In addition the committee itself was held monthly and there was a waiting list for each submission, so an application could take time to be reviewed and the appropriate panel convened (there were four panels in total and I had had the pilot reviewed by Panel A and was applying now through panel D). However in March 2004 the review process had changed. I found this out after applying for approval and being informed that the wrong application had been used and I would have to apply all over again. The new form was through the COREC which was an internet based application. This new form was very unforgiving and it took some time to re-jig the existing application form to meet the format of the new internet based form. The internet form was not sufficient for the application, so had

to be printed out in full in addition to the copy in cyberspace. Additionally, under the research governance framework within the school, it now became necessary to gain ethical approval from the University itself before any further applications could be made. This came back favourably in October 2004. By this time the application adjusted to meet the new format had been received by the LREC, who themselves had to adjust to holding their committee with the applicant present. I now was called to attend a meeting held by Panel C, the third of four Panels that the project had encountered since its inception.

I received a telephone call from an administrator in the LREC inviting me to attend the review of my application. She realised it was short notice but asked whether I would be able to let her know, now, if I would be able to attend, it was the following Friday at 12:15 in an outbuilding of the local hospital. The following Friday, I arrived at 12:10, and was signed into the building by the receptionist and ushered upstairs to the waiting area outside the committee room. I decided to go to the toilet as I was a little nervous, not sure of what to expect, and it gave me an opportunity to remove myself from the pile of '*Women's Own*' and similar magazines that littered the coffee table in front of me. The environment was not unlike a doctor's waiting room, just eerily bereft of people, coughing and telephone rings. The building was modern, a non-place (Auge, 1995), a cross between an airport lounge and a shopping arcade with a wide central walkway with offices either side that gave the impression of space but the couch I had set up space in remained a doctor's surgery. A quarter of an hour later, a lady, whom I later found out to be performing secretarial duties for the meeting, cheerily told me that another meeting had been scheduled before mine; the representative of that project had not arrived and that I should wait for them to be seen first, when they did arrive.

So I sat there in my suit and tie (something that does not sit well on my, then, hirsute frame), sweating because of the heat of the late September afternoon. Sitting, sweating and quite nervous, I pulled a book from my bag and started reading it, trying (with little success) to concentrate on how Bourdieu's insiderness could or could not fit with an epistemological position from which I came. I simply underlined a few sentences making notes in the margins, highlighting the page number and rough topic in a home-made index on the inside reverse cover of the book. By 12:45, it must have

become clear to the panel that the absentee researcher would not attend the review of their project and so I was ushered into the committee room (by the lady who asked me to wait for what seemed longer than it actually was), a little more nervous and sweaty than I was on arrival. The Chair introduced herself and informed me that she had helpfully asked the entire panel to turn their name cards to me in order that I could witness who it was that was speaking. The room was a boardroom, I was ushered to the remaining seat and an effort was made to introduce me to the rest of the panel. First, the gentleman to the left of me on this committee table, Professor 'Jones' the nurse representative who informed the chair 'oh I already know Paul', and then to three other members, the six others were only referred to in passing. The ethical review panel were from a wide variety of backgrounds a retired mathematician, a general practitioner, a dentist, a statistician and the second and third lay members (the chair was also a lay member).

The first question came from Professor Jones who said that he had read through the application and that what I was proposing didn't look like any kind of ethnography that he had ever heard of. He further pointed out that he had performed ethnographic research in the past and my research was not what he would consider to be 'an ethnography'. Needless to say I was stumped on my first question, a question that I was totally confused by. Not sure what relevance a methodological question had within an ethical committee meeting I attempted to explain what was meant by ethnography within a social science department and how it was necessary to observe practices and interview patients after their time within intensive care. I was informed again that the intensive care unit was unaware of the proposed research. So, I pointed to the relevant parts of the application form and covering letter, they seemed unimpressed.

One of the lay members appeared concerned that I would be approaching family members at a time of heightened emotional states, I replied that as per the research protocol the consultant on duty for the day and the nurse in charge of the intensive care unit would be approached in the first instance in order to short list appropriate candidates. Following this, the nurse caring for the patient (the intensive care unit at the time had a policy of allocating one qualified nurse to each individual patient) would be the final person I would approach in order to speak to family members.

This had been emphasised through all research protocols and application forms thus far (and is reproduced here in the appendices), as it was felt that this person would have a far greater understanding of the dynamics of the family (such as whether or not the family were coping with the experience of intensive care) as well as the individual patient. I went on to say that as an intensive care nurse with over four years experience, I was familiar with talking to family members about difficult issues at very difficult times, such as issues surrounding organ donation and would be able to talk about involvement in the research with sensitivity and respect. She thanked me for my comments, and the chair invited the next speaker. The chair stated that the patient and staff information forms were too long and that the research project should have a change of title, she did not like the title at all she told me. I explained that the forms were based upon changes from the original format according to the response of the previous committee and that changes to the title would require validation from the Economic and Social Research Council.

“My daughter was in intensive care”, set up the next speaker’s position, “and I would never consent to anybody talking to me, or my daughter.” She went on to explain that not only was her daughter on a life support machine but that she needed kidney dialysis, and neither she nor her family knew whether she would ‘make it’ out of intensive care alive. The research ethics committee requires unanimity in order to pass projects and so far I had received two major obstacles to the research ever receiving approval. I attempted to explain that the perspective of survivors of intensive care was extremely important, policy had altered which may impact upon patient experience, yet this was anecdotal as no research had been performed among this population. Major shifts in the organisation of intensive care provision had been made which failed to take into account the voice of the patient and there was no clear idea about what the patient perspective might actually be. She stated that her daughter had no memory of intensive care, all she (her daughter) knew was what her family had told her and as such it would be pointless interviewing her, particularly as she would find the interview distressing. I agreed that few patients have a memory of being within intensive care, particularly whilst sedated and paralysed (a form of general anaesthesia), but that having no memory of the event can be as significant, if not more so, than if she had had a memory of it.

In Latour's (1987) terms, this is 'the stop'. The mother makes explicit that which is a legitimate form of research in intensive care, she presents herself and in turn is accepted as an authority on such matters. In turn the worldview has shifted to her perspective. There can be only one answer to a question, as made explicit in Chapter Two and the answer to whether or not ethnographic research is legitimate within intensive care and that which involves patients in particular has been answered fairly clearly. The mother, the individual (Cohen, 1994; Rapport, 2003) holds power and this power is mobilised against the possibility of ethnographic research within intensive care. 'My daughter has no memory' can be read as intensive care patients have no memory and any attempt to access patients accounts can be deemed illegitimate from the outset. Within the context of a mother looking out for her daughter any counter position becomes untenable, the care of the young becomes a concept that holds (Latour, 1987). The suffering associated with memory loss becomes academic and the potential for harm becomes real and legitimate. In short, ethnographic research within intensive care in this instance cannot be read as legitimate. To talk to persons and witness the individual within a context of the performances of organisations cannot be seen to be legitimate areas of research. Ethnography becomes dangerous because ethnography becomes an occasion for speech, a possibility emerges that something may be said and this cannot be legitimated at a point in time in which communication is constituted as a dangerous activity. As the subaltern can never speak (Spivak, 1999), neither can the intensive care patient.

The chair intervened, and stated that interviews would not be undertaken with the patient, if they were to be conducted they should be with family members, but only after discharge of the patient from intensive care and by implication the High Dependency Unit. I again re-iterated that interviews with patients and family were important, particularly as family members in part re-construct the experience for the patient and the way that this is done is of great significance. This, the chair added, was an academic issue, not one that would benefit patients and therefore was not worthy of ethical approval. She went on to say that she could see no reason for observing practices within intensive care, particularly as patients would not know what the practices might actually be, therefore observing organisational practices

would be a pointless intrusion on the rights to privacy that the patient, their family and the intensive care staff have a right to. I was stumped.

As made explicit in Chapter Three, there are certain assumptions about what intensive care is about and what one accomplishes. Within the media, it is seen as a place of great significance, a space between life and death and a place where the latest life-saving medical technologies reside. However, the means through which intensive care defines itself is a legitimisation of rights to access, in such light it can be viewed as both legislator and interpreter of whom is deemed a legitimate intensive care patient. Should an interpretation be made that a patient is an illegitimate admission, what are the consequences for that patient? Issues concerning mechanical ventilation and the history of intensive care are not necessarily as clear-cut as much of the medical literature surrounding the development of intensive care would suggest. The medical and nursing staff of intensive care understand their position through histories taught within lectures as part of their post-graduate training, suggesting a recursive dimension (Giddens, 1986) to legitimating intensive care practices. These as part of the ethnography are taken as cultural assumptions, through unpicking some of these assumptions a context emerges through which intensive care can be read ethnographically. This is why the presentation of different aspects of intensive care as a specific cultural space were highlighted within Chapter Three and will be referred to through the rest of this thesis, but of course within the confines of the LREC meeting they were not deemed legitimate modes of enquiry.

I felt it necessary to develop an ethnography of the organisation and practice of intensive care in order that a context from which the patient experience would be set. More significantly, certain practices on the part of intensive care staff and family members are performed but not necessarily recognised. That is, certain things are done in the social world which people have taken as the way to act or behave which doesn't necessarily relate to conscious thought, a sort of tacit performance of being social. These performances are those that would be lost in a research project that was based solely on interviews and I was adamant that they remain, whilst the review committee were similarly adamant that they be omitted. It was clear that the ethical review committee would not be moved on this issue, so the next Panel members were invited to talk. Only the man on the right of me spoke, the debate had swung around

the room counter-clockwise and he suggested that I liaise with Professor Jones in resubmitting the application form. By this time I think I had had enough, having waited for so long in the heat to then have myself, my research, and the abilities of my supervisors seemingly insulted, I began packing my papers. I was told by the chair that the study was worthwhile, but that I would not be given ethical approval so I stood up, picked up my bag and left the room. I stood at the bus stop and telephoned Dr Latimer (my supervisor). I was very frustrated. Professor Williams (my second supervisor) rang and arrangements were made to meet in order for the next application for approval to be made. Indeed, it was also suggested that I undertake the PhD with a more theoretical base, using the pilot data (of which there was a huge amount, more than enough for a PhD in its own right), which would circumvent the need for ethical approval. However, I wanted the project done in the way I had envisioned it from the outset.

I received a letter from the ethics committee a week later stating that [emphasis in original letter]:

As discussed with you at the meeting the committee expressed concern that the aims and objectives of your research were not clearly identified. In addition, the committee could not understand the link between your primary and secondary objectives. This was very important factor in a research study that investigates experiences of critically ill patients who require treatment within an intensive care setting. The study in its present form could prove to be very distressing to this vulnerable group of patients and their families

The committee found it difficult to determine why the study had to be conducted whilst the subjects were in the Intensive Care Unit and unable to consent to involvement in the study. Members were of the view that the study could and should be conducted when subjects had been discharged from the Intensive Care Unit and were able to consent to participate in the study. Members agreed that you should be looking for views of patients and their relatives, following the patients stay in the Intensive Care Unit, as this would unquestionably be less stressful to all participants.

Members were of the view that all the information sheets were too long and the language used quite complex. The standard information sheet format (available from the LREC office or the COREC website) had not been followed, information sheets should be provided in a larger font and should be shorter and to the point whilst detailing all the key factors of the study.

It was not clear whether the Consultants in the Intensive Care Unit were aware of and had agreed to the study. No supporting letters from the Consultants in charge of the ICU had been provided. Members were of the view that a research study of this nature could potentially be very disruptive to the ICU staff.

The patient information sheet stated that the study had been reviewed by the *** NHS Trust, The Economic and Social Research Council, Academic Staff at Cardiff University and Senior Clinical Staff in the Critical Care Directorate in ***** NHS Trust. However, no supporting documents from any of these institutions had been included in the application.**

I regret to inform you that the application is therefore not approved.

As discussed, Professor [Jones] would be willing to meet with you and your supervisor(s) to help revise your study in order that a resubmission could be made to the Research Ethics Committee, if this would be helpful.

This letter certainly did not make what was a horrific experience, defending my work against a team of people who were trying their best to ensure the project never made it to fruition, any easier. I was appalled at the behaviour of the panel in the first instance and dismayed by the fact that the letter suggested that they had not listened to a great deal that I had said during the panel meeting. So a fourth application was submitted which took account of the issues raised by the latest review. The Chief Consultant, who by this time had had a substantial period of sick leave and had now returned to his post (following hospitalisation for a spinal fracture, subsequent rehabilitation and recovery), had agreed to be the Principal Investigator (applicant responsible for the project), Dr. Latimer became the Chief Investigator, myself and my second supervisor, Professor Williams became on-site investigators responsible to the Chief Consultant (or principal investigator). The information sheets and consent forms were shortened to two pages and provided with size 14 font as opposed to size 12 for those with visual impairments. Some other, very minor, alterations were made and the application was resubmitted in January 2005.

As Chief Investigator, Dr Latimer began liaising with the administration staff of the LREC, seeking clarifications. She attended the LREC meeting with me, taking a supporting role so that should I appear to have not quite answered the questions appropriately, she would step in. On entering the meeting this second time (new regulations stipulated that there was some degree of openness required now), the panel were waiting and were composed of almost the same cast as previously. From my perspective, the panel presented the same Kafka-esque forms of the previous meeting, but as each question was in turn dealt with these faces began to soften. The perceived underlying hostility of the panel began to disappear, with one exception. Slowly during the course of the meeting, the emphasis turned to how important a study such as this actually is. Of course the lady whose daughter was in ICU still refused to accept that such an investigation had any worth, but gradually the panel (rather than we the applicants) began to wear her down to the point that she could not realistically argue against the project any more on the basis of her daughter's

experience. Yet she remained adamant that certain things, such as speaking to the survivors of intensive care should not happen.

Other panel members began to disagree with her sentiment and eventually the panel agreed that the research should go ahead, with some further alterations to the paperwork (this was the fourth time it had been altered and each time it followed on from the previous panels recommendations). By the end of the second meeting the chair in her closing talk stated that this was a very worthwhile piece of research which could have very positive implications for patients who are extremely ill and vulnerable and will enable a voice to those who otherwise would not have any input into the care that the critically ill receive. On this occasion there were four lay representatives, a nurse, a pharmacist and a dentist, Professor Jones who argued that the research was not in his opinion an ethnography was absent. However, the paperwork required three further submissions before they were approved and the final information sheets that were submitted and approved were virtually identical to those submitted to the first research committee (from panel D) along with a single page abridged version. The paperwork had virtually turned full circle. In the end, no concessions were made on how to do the ethnography, but by the time the final approval letter had come through (the 10th of June 2005), I had only 2 months of my PhD studentship left, which left no time left to actually do the research.

I now had to return to the research site quickly and actually 'do' the research. It had now taken 22 months to gain ethical approval from the LREC from the first submission and 26 months from the point at which I had to apply for an honorary research contract. Time was now against me. I sent letters back to the research site explaining that the delay was due to not having received ethical approval and that I would be starting the research forthwith. Ironically, I was informing the Principal Investigator, who if a system paid more than lip service to professional titles would actually be aware of this already. However, I felt obliged to apologise on behalf of the LREC on account of asking them to perform duties above and beyond their clinical and managerial responsibilities, the LREC delay reflected badly upon me. On meeting up with the Chief Consultant (or was it P.I.), he was still happy for me to perform the research, however, the unit had reached the quietest period he had known for a long time.

I regularly visited the unit, spoke to the nurse in charge of each shift, the consultant in charge of each shift and met the response that the unit was extraordinarily quiet and that maybe I should come back again tomorrow. In desperation, I called in a few favours, interviewing different members of the medical and nursing staff, but by now it was far too late to interview or follow up patients and my material was based upon a broad ethnographic investigation with a few interviews in between. The ESRC had given me 33 months to complete the PhD, I was now beyond my studentship and the possibility of finding funding up until October seemed slim. However, with help from the school I was able to receive ESRC funding up until the end of September.

It was now far too late to conduct the research and I was in a position of desperation. I made an appointment to see the head of school to see if there could be any way of securing funding from the school. I was told no, at least not until I had tried and failed at every other possible avenue of securing additional funding first. He spoke with another senior academic within the school who suggested that many PhD students write-up whilst they were 'on the dole' and that I should speak to somebody in the student union. I dutifully visited the unemployment office in order to 'sign on' which if accepted would give me an opportunity to apply for housing benefit and thereby not get evicted from the house I rented. When I visited the Student Union, I was informed that there was indeed a hardship fund and I would have no problem in getting it, given the case I had made, in order for me to 'write-up'. The hardship fund would be for four months, however, some would be taken back to account for my jobseeker's allowance. The experience of seeking housing benefit and negotiating the employment office is worthy of an ethnographic account in its own right; suffice to say I returned to work as a staff nurse in intensive care in November 2005. At this point I had thoroughly lost interest in the research.

Chapter Six.

The Embedded Body and the Embodied Bed: unconscious heterogeneous bodies within heterotopia.



Picture 6.1: Bed Space in Field Site (Bed 4 in Appendix Four).

Introduction.

Within the previous chapter some of the issues encountered whilst attempting to gain ethical approval and the process of gaining such approval were presented. This made reference to those institutional processes that within the analysis held a certain level of visibility and obscurity. Working through, writing up and expressing argumentation within the research necessitated a particular, pseudo-scientific bureaucratised form of communication to be deemed worthy of the review panel. The research needed to be represented in a way deemed legitimate to the Local Research ethics Committee (LREC) panel. These institutional practices, which formed the bulk of the chapter's empirical presentation, were viewed as accomplishments. The agenda of the committee could only be viewed as an artefact through the meetings held and the textual correspondence. However, these cultural materials (texts) and artefacts (assumptions) enabled an insight into the cultural practices of the LREC from a particular position, a construction of the LREC as accomplishment. These practices

did not necessarily hold any reference to either principles of ethics or the conduct of the research but were rooted within commonplace (mis)understandings of what constitutes intensive care. In itself this revealed a particular personal stake in whether the research should be allowed to be conducted or not in the first instance. Talk and interaction which are key components of ethnographic research (among others) became couched in terms of risk, threat and accountability, exacerbated by the fact the research was to be conducted among speechless critically ill patients and their families. To invoke the words and discuss experience of intensive care among the ethics panel and latterly to a single member, constituted a real danger. This danger could be seen as embedded within a particular form of social world, constructed through strong emotional discourses of embodied experience. In this way, the following chapter (re)presents ideas of the body, of machines, of embeddedness and embodiment (Collins, 1996; Collins & Kusch, 1998) in relation to a particular reading of intensive care.

This following chapter ties in with the opening empirical chapter by demonstrating the multiple readings (Mol, 2002) of the unconscious body. These readings are made visible through both extension to material artefacts, such as mechanical ventilation (Place, 2000) and to other persons, such as family (Happ, 2000), or other members of the health care team. This encompasses the means through which the body is made visible to those around it in numerous ways, not through the commonplace means of speech and interaction but through extension to other medical/cultural artefacts. The body, as both the focus of the gaze over technical artefacts and the technical over the bodily artefact are implicated in the production of knowledges surrounding the unconscious body. Rendering the body legible occurs both of itself, through extension to cultural materials such as the vital signs monitor or urinary catheter, and of the cultural artefacts (interpretations of the materials) through extension to the body. This is in part a chapter about the spaces which the unconscious body inhabits, physically and metaphorically, and the spaces through which it is made knowable. It is about making sense of a body that requires a specific set of knowledge practices to be able to interpret symptoms, when symptoms cannot be voiced. These accounts of the body can be concretised, forestalled or discounted. It is about a body that within a strictly biomedical context demands a reading through signs and perhaps more importantly, an observation and translation of those signs moment to moment.

This chapter will emphasise the heterogeneous nature of the unconscious critically ill body within the intensive care unit as distinct from other readings of the body. Whilst it is recognised that an important aspect of the reproduction of bodies and their inscription (Latour, 1987) is through the analysis of medical records (Berg & Bowker, 1997), this is not central to the chapter. The means through which the body is interpreted, the means through which knowledge is produced within the documentation, who claims the documentation and what does not make it into the text is of equal if not greater significance (Latimer, 2004). Whilst the heterogeneous nature of the body is reproduced through records, this chapter aims to highlight the heterogeneity of the body through clinical practice as opposed to cultural artefacts that hold (Latour, 1987). Specifically within intensive care, bodies of the unconscious are rendered legible in distinct ways, and this legibility can radically alter depending on the context of the interpretation. This rendering legible, as will be demonstrated, remains, irrespective of the bodies' immediate presence or absence.

The body in abstraction becomes a site whereby allegiances to a certain discursive formation are performed (Foucault, 1972), each with their own particular readings and accomplishments. These readings each with their own epistemological and ontological frame can be invoked in order to justify a certain position from which action can be taken. The microscope in Atkinson's (1995) haematological laboratory becomes a useful trope for learning a particular mode of seeing a means from which the body can be read in relation to its tissues. It is specifically this discursive aspect of the gaze that is not made explicit within Atkinson's rendering of legibility. Of course, it may be implicit in his accounting for the rendering of legibility, but within this context it is important to emphasise why the term legibility is used and what that is taken to mean, specifically in this reading of the body within intensive care. The following accounts of rendering the body legible within intensive care are in part a making sense of the body in a particular way and a legitimisation of the way that the body becomes a particular body through the methods that analyse the body (Luhmann, 1990). It is an ontological and epistemological position from which the body can be simultaneously read, inscribed and described which in turn becomes the only legitimate way that the body can in fact be seen, at least for a time.

For the purposes of this chapter legibility can in part be equated to the clinical gaze (Foucault, 1973) with its attendant notion of the discursive formation. It in part represents how the body is read and made legible in relation to a certain way of knowing, such as in Atkinson's account of learning to read cytological and histological microscopy slides (p. 74-78). There is no issue with the idea that the representation of the body selects and transforms particular features of the body that in turn become the way that the body can be read within a specific context (Atkinson, 1995). However, the multiplicity of means through which the body is read within different contexts is highly significant (Hacking, 2000). There are certain biomedical means through which the body can be read, but it is also read as a moral body, a leaky body, a body without margins, a problematic body and certain discursive formations of the body are invoked in order to lend weight to a particular course of action. Significantly, for choosing the term legibility, it is when these things are written down, that they are in part settled as a legitimate representation of the patient's condition (and by implication, needs) that form a particular cultural material. Which is chiefly why this chapter refers back to legibility as a trope, not just to the normative and normalising gaze, but the practice of writing and detailing observation that constitute such a large part of nurses' work within intensive care. It is a trope as the act of writing in itself transforms the way the world can be perceived (Plato, 1995; Derrida, 1976) and by implication the way the body is read, in the way charts allow certain things to be documented and ignore other aspects of the body and its treatment. It is a trope as the ways in which the nurses' work is reduced in compliance with the format and timing of the routine hourly observation documentation (Garfinkel, 1967; Luhmann, 1990). The means of legibility on a chart or in the medical notes becomes the means through which the body can be legitimately read. The practices and the structures which enable them, give rise to a normative and normalising gaze as will be seen through the representation of the ethnographic work analysing the unconscious body within intensive care. So legibility becomes a series of cultural practices, the mundane physical work of typing and writing of physiological information are examples of these cultural practices and as a consequence through inscription the body is made visible as a cultural object.

The embedded body and the embodied bed.



Picture 6.2: Inhabited Intensive Care Bed Area (an embedded patient).

Unconscious patients are predominantly admitted to the ICU through three main routes; either from a general ward, whereby they have been resuscitated and intubated on the ward as part of the resuscitation, from the Emergency Unit (hospital transfers with medical, nursing and paramedical attendance also occur through the Emergency Unit), or straight from the Operating Theatre. If for example a conscious patient is admitted who will require invasive mechanical ventilation (as is generally the case), intubation equipment which is located in a specific tray (which are pre-packaged by the technicians) and anaesthetic drugs such as a paralysing agent, sedative drug and in some instances analgesia will have been prepared by the receiving nurse or doctor. Often resuscitation fluids which are used to counter the effects of the anaesthetic agents will also have been prepared (predominantly by nurses) and rarely after being instructed to do so by medical staff. Indeed if a particular intensive care consultant is on duty, and the nurse is fairly senior (up to two years is generally viewed as junior by those nurses in charge of the ICU), the nurse will generally know exactly which combination of drugs that particular consultant, or advanced trainee will use or is most likely to use. So before the patient arrives preparations have been made to welcome them into the fold, to become an unconscious intensive care patient.

Those admitted from the Operating Theatre have the intensive care bed allocated pre-operatively and the theatre porter collects it peri-operatively. It is prepared by the receiving nurse, who places an oxygen cylinder, portable monitor and Ambu-bag onto the unoccupied bed for transfer back into the intensive care unit. This means that immediately after surgery the patient is transferred from the operating table onto an

intensive care bed which has been 'prepared' with the basic tools with it to provide a safe transfer to the ICU. On arrival, generally with an anaesthetist, nurse, technician or Operating Department Assistant (ODA) and porters, the unconscious patient requires movement into a designated position within the intensive care bed space, which is the space between the ventilator (which is generally situated on the right hand side, unlike the positioning in Picture 6.1) whilst on the other side drip stands and numerous other pieces of supportive equipment are located. The bed is stopped short of the work space behind the bed where the medical gases, suction equipment and manual ventilation devices such as Ambu-bag and Waters Circuit reside. Then there is enough room at the head of the bed for intensive care staff to get behind the bed easily should they need to. So the patient is positioned facing away from the wall and the windows and arrives in the nurse's 'bed area'. With the odd exception the space remains the nurse's bed area being referred to by the name of the nurse not the patient. Even after a shift change, when the nurse 'hands over' the patient to the receiving nurse, it remains the nurse's bed space unless the patient becomes a long term resident which is loosely defined as over a week.

Those unconscious patients admitted from other hospitals arrive with an entourage of support staff, intensivist or anaesthetist, nurse, technician, porters and ambulance crew. As with transfers from within the hospital the first task for the staff is to remove them from the ambulance stretcher or 'ward bed', as general ward beds are known, into the intensive care bed. It is only once the patient is in an intensive care bed and in an intensive care bed-space can the proper work of examining and treating the patient happen. The exception would be those patients still requiring resuscitation on transfer, or who arrest during or on arrival. On its own this exception usually invokes a heated discussion between the receiving nurses and doctors and those involved in the transfer as it demonstrates to intensive care staff a lack of appropriate monitoring and treatment of the patient's condition as they should always be 'stabilised' prior to transfer, that is according to blood pressure, heart rhythm strip readings and recent blood gas analysis. This is largely because the hospital corridor or lift is not seen as the appropriate space for doing resuscitation as there is a minimal amount of emergency equipment and no telephones to request immediate help. But perhaps what infuriates intensive care staff more is the transfer of the recently deceased patient, who may have 'expired' during transfer or immediately prior to transfer as this

requires intensive care staff to certify the death and speak to a family they have never met before, explaining a death that they have had no part in trying to avert. But even so the transfer is made to the intensive care bed for last offices to be performed.

Having arrived in the bed-space, and transferred to the ICU bed, the patient is still not necessarily a 'real' intensive care patient. They have to be 'hooked up' to the monitoring equipment if they have already been 'prepared' by others, such as the previous hospital, or operating theatre. Otherwise, these specific sets of procedures need to be undertaken in order to transform the 'sick body' into the 'critically-ill' body. And through the insertion of monitoring devices such as arterial lines, central venous lines, urinary catheters, endotracheal tubes, drains and so forth which puncture, breach and open the body, only then can the body be made sense of, be rendered visible to intensive care staff. Yet the body remains an object of treatment and of assessment, through the ceremonial (bureaucratic) order (Strong, 1978) of becoming an intensive care patient any residual unnecessary aspects of the person are stripped away, or hidden. The subject associated with social theory becomes an object, with any agency associated with personhood being rapidly made redundant, if that is the patient arrives with any. As one of the senior medical staff remarked to a new intensive care nurse:

'...our patients leave any autonomy they might have on the other side of the door [to intensive care] on their way in...'

(From field notes)

But at least he implies it is left there to pick up once they are discharged. Should a patient arrive who is conscious, there is a specific way through which their body is rendered legible to the intensive care staff.

As already noted the most pressing issue once the patient arrives in the ICU is to transfer the patient onto an intensive care bed, apart from the previously noted exceptions. Once they are in their proper place the process of initiation can begin. The number of staff involved in the initiation depends upon the workloads of the unit and the severity of the illness of that particular patient and in certain circumstances whether the consultant on that shift is expecting the admission in the first place. Occasionally a patient will be admitted (or at least an attempt will be made to admit), who the intensive care staff were unaware of. Predominantly this will occur when a

patient from another hospital, such as those patients requiring neurosurgery who find their way to the intensive care unit. They may have been accepted into the hospital by a consultant neurosurgeon, but if they have not liaised with the intensive care staff then they run the risk of non-admission, in part as the process of admission was not legitimate.

A patient on a stretcher with a nurse, anaesthetist, paramedic crew and porters arrived at the entrance to the ('B' Side, see Appendix Four) of the intensive care unit. An intensive care nurse walked by and saw them and opened the door. As there were no expected admissions or transfers, she asked where they were going. The anaesthetist replied that they had come from a District General Hospital in a nearby city and gave a brief account that the patient had been accepted by the neurosurgeons. The consultant intensivist who was on shift that day walked out of the coffee room to see an intensive care nurse, a group of unknown staff and a ventilated patient on a stretcher in the corridor. The intensivist asked the team where they thought they were going, to which the anaesthetist replied that this patient had been 'accepted' and he was taking the patient to intensive care. "No I haven't" replied the consultant, the anaesthetist repeated that the patient had been accepted and required stabilisation within intensive care. "I am the consultant in charge of this intensive care unit and nobody has told me about this patient's existence let alone having accepted him". It was suggested that they find their way to the operating theatre down the other end of the corridor.

(From field notes)

The patient did arrive following neurosurgery, and shortly after the corridor encounter the consultant neurosurgeon came down to the unit and spoke to the intensivist about the patient and asked if he could have a bed for this patient in intensive care. From the intensivist's perspective, at that time there were beds but not enough nurses to take the patient unless one of the nurses in charge took the patient *and* remained in charge of the unit, which is deemed an unsafe practice. On another level it was viewed as a devious route to gain admission; who could refuse admission of a critically ill patient after all, particularly one that is in the entrance corridor to the intensive care unit. But more significantly, it demonstrates how difficult it can be for a patient to get into a bed within intensive care and more importantly traverse the proper route to get an intensive care bed. There has been a period whereby a great deal of emphasis had been placed on inappropriate admissions to intensive care (Smith & Nielson, 1999) that in turn led to admissions largely being dictated on a consultant to consultant basis (Ramsey & Hawksworth, 2002), but in practice this has a greater impact on whether or not the intensive care consultant will review the patient and determine the appropriateness of admission. It is through being transferred onto an intensive care bed (which when occupied becomes the patient's bed, unlike the bed area which remains the nurses) that in part constitutes the new status of being an intensive care

patient. You can be critically ill in the corridor but that doesn't necessarily make you an intensive care patient, at least not yet.

On admission to the ICU, the body of the unconscious patient is of the utmost importance. However it has yet to gain any intrinsic value until it has been transferred onto a bed, that is the body needs to become 'embedded' within the intensive care unit. Once the body arrives in the nurse's bed area it becomes the responsibility of the admitting nurse and the process of sorting out the body can begin. Usually at least one or two other nurses will assist with a doctor who will usually be a Senior House Officer (SHO) or registrar, unless the patient is particularly sick (or the unit is particularly quiet) in which case the intensivist will be present. The admitting nurse will receive handover from the transferring nurse or doctor which may be a brief outline of the patient and their treatments so far, whilst the other nurses and doctor attend to the new patient. Or they will continue 'sorting out' the patient whilst listening to what the transferring nurse in particular, and to a lesser extent doctor, has to handover. In part this reflects the legitimacy that the transferring team hold in the eyes of the admitting nurse. Should the patient be received from the operating theatre, intensive care staff have little faith in what the transferring nurse has to say as it generally amounts to an account of the drains inserted (which are visible), the procedure itself (which is already known) and that they have an arterial line in-situ, which is self evident by the time the theatre nurse has stated this as the nurse, or her colleagues have already 'hooked it up' to the monitor. What the intensive care staff want to know is about blood loss, figures such as serum lactate and potassium levels, problems with intubation and ventilation and the current ventilatory settings. But this is within the anaesthetists' realm and often their account is listened to as opposed to the almost irrelevant handover from theatre nurse to intensive care nurse, but from the theatre nurse's perspective this is an important aspect of the nurses' role. For the intensive care nurse, it is of a lower level of significance, partially because it doesn't tell the nurse what it is she needs to know. Whereas the theatre nurse has an obligation to impart this information, the intensive care nurse may often be demonstrating an obligation to not listen too closely and may well be doing something they consider to be more important.

What is known of the intensive care patient prior to admission generally includes gender, age if particularly young or particularly old, significant pathology, injury or when not known the circumstances surrounding the patient's requirement for intensive care such as Road Traffic Accident (RTA). If the reason for admission or story surrounding it is unusual, such as snow-boarding down an artificial ski slope on a For Sale sign, falling down a lift shaft or violent attack such as being struck in the base of the skull with a claw hammer, or having received multiple stab wounds, this is generally sufficient and provides a certain premise from which the bed area can be prepared. To some extent this also allows intensive care staff to indulge in certain assumptions about the person through the means by which the body has become injured.

If a larger detailed list of presenting and underlying pathologies is produced then other assumptions are brought into play. For example, Sharon a nurse with six and a half years experience in intensive care, was informed of an impending admission from the Emergency Unit (casualty) by the Registrar:

She would be 'taking' a seventy two year old morbidly obese man with a chest infection who has high blood pressure, peripheral vascular disease, diabetes, is wheelchair bound, has had a stroke, a right above knee amputation, smokes twenty cigarettes a day and lives in a nursing home. He has been intubated in casualty and needs ventilation, haemofiltration [renal support] and possibly inotropes [drugs which increase blood pressure through increasing cardiac muscle contractility]. Sharon's response was 'what the hell do they expect us to be able to do for him here' to which the registrar laughs'.

(From field notes)

The negative gloss that Sharon painted of the patient concerns a host of bodily and social issues. Whilst supportive therapies may be provided the problem is getting the patient off those supportive therapies and back home again. The patient is unlikely to recover from this recent infection owing to the other issues and may not have been admitted if it weren't for the fact that he was now intubated and reliant upon mechanical ventilation. By intensive care's own definition of what it should do and who it should treat, its rules of engagement, are predicated upon a notion for 'potentially recoverable disease', it is the nature of potentiality in the individual circumstance that is open to a wide degree of interpretation.

This particular set of co-morbidities associated with this patient sets up very specifically for the nurse what sort of body she will be dealing with and if we involve

the person, it suggests that the patient has a pattern of ignorance of health advice, at least from the perspective of the intensive care nurse. When asked by other nurses who she is 'getting' she gives an account of his history that amuses her colleagues. Similarly the 'For Sale sign snow-boarder' provides a potted history of who this person is, the work involved (which will focus on the body) and gives rise to counter admissions from the other nurses 'I was working with Shana last week and we had a patient come in who...'. The body of the soon to be intensive care patient is read from the initial information gleaned from a telephone call and within this, aspects of the personality of the person are similarly being read and interpreted by intensive care staff. But these things to intensive care staff are in some way conjectural, there is a slight distrust of others' accounts until the facts are presented before them but for these facts to be elicited a body needs to be presented before them, so that a start can be made on reading the body proper.

We've hardly got to the actual body yet, but it will come. What has been attempted is the provision of a context from which the body is read by intensive care staff. The patient's body needs to be allocated a certain position within a certain bed space. That space is to all intents and purposes the nurse's bed space even though it will become an (un)natural habitat for the critically ill. That is, a tautological natural habitat for a critically ill body, but an unnatural habitat for persons. Yet the bed remains the patient's and is referred to as 'the patient's bed'. The space however is referred to by the nurse's name and by implication the patient, who now 'belongs' to the nurse, is located in his own bed which resides in the nurses space. It is only once the 'embedded' patient is located within the nurse's space that the body is in a position to be rendered legible. Until the body has been rendered legible it has little intrinsic value; there is little that can be read from it. To be rendered legible, which is the subject of the next section, it is necessary for the body to be opened up, breached and punctured and as I shall argue assimilated into the bed space through the technology.

So at this point the person is stripped of agency, at least from a certain perspective (see Chapter Eight) in order for the 'body work' of assessment, observation and treatment to be conducted. If there was an embodied subject admitted to the ICU, such as an awake, vocal patient (which occurs quite frequently), the embodied subject is translated into a disembodied object through anaesthesia. This object of medical

attention is then embedded into the ICU into a distinct space, the bed space. Once inside this space from which knowledge about the body can be accrued, through various means then the work of the intensive care staff can be commenced and the body can become known. However, there is a rudimentary knowing of the patient by intensive care staff developed through a knowledge of the body and those bodily issues associated with the underlying disease or injury or its circumstances. The body and the person are being read *in absentia*, but until the patient arrives and gets sorted out, it remains a rudimentary knowing. Even if it is an accurate account of the body, it means little until the patient is ‘embedded’ into the intensive care unit, in the flesh.

Bodies without meaning.

The patient had been transferred to the bed (bed 12 in Appendix Four), Elizabeth is now ‘sorting out’ the patient, taking baseline physiological observations and ‘turning her into an ICU patient’ through the insertion of various lines and tubes, and hooking her up to the monitor. She is working on the patient’s left side whilst the registrar is trying to place an arterial line in her right arm. “I’ve got blood on the sheets” the registrar shamefully admits. “Don’t worry” replies Elizabeth, “she’s pee’d the bed anyway”. There is a foul pungent smell from the bed area, the registrar and the nurses are busy performing the ‘sorting out’ ceremony.
(From field notes)

The body of the unconscious patient within ICU as previously noted has little intrinsic meaning in itself. It needs to be ‘sorted out’, rendered visible and displayed in a meaningful way to intensive care staff. The question still remains though about what ‘sorting out’ a body entails. From the point that the patient is transferred onto the intensive care bed the ‘sorting out’ can begin. It is, by way of example, more comprehensive to detail the sorting out of a patient who has yet to be paralysed and sedated therapeutically, as opposed to those already ‘sorted out’. The issues, however, remain pretty much the same but have slightly different social implications. From the account of the staff nurse and the registrar in the opening quote, who are working together to sort out the patient we can glean a good idea of the ceremonial order. The ceremonial order is further exemplified through the ward round and in particular the major spectacle is the weekly microbiology round². This particular patient was transferred to the unit from the hospital emergency unit. She was admitted as a result

² The ‘Micro Round’ as it is known has a group of up to four medical students (as a rule but there can be more or fewer depending upon the academic year), at least one consultant who specialises in infectious diseases and their ‘team’, intensive care doctors but not generally the nurses (who feel they have been ‘let off’ from this particular spectacle) and is led (or presented) by the intensive care consultant).

of ingesting a large cocktail of prescription and non-prescription pharmaceutical agents and washed down with a bottle of vodka. Whilst this 'reason for admission' provides the intensive care staff with a certain idea of who this person is and as mooted previously, their relative moral worth. This however is not the subject of this section. What is significant is that the intensive care staff are working on their respective roles. Elizabeth is charting a set of baseline observations from which the patient's clinical condition can be judged over time. But even a few minutes after being admitted to the ICU, a lot of the work involved has already gone past without comment. Some gaps need to be filled.

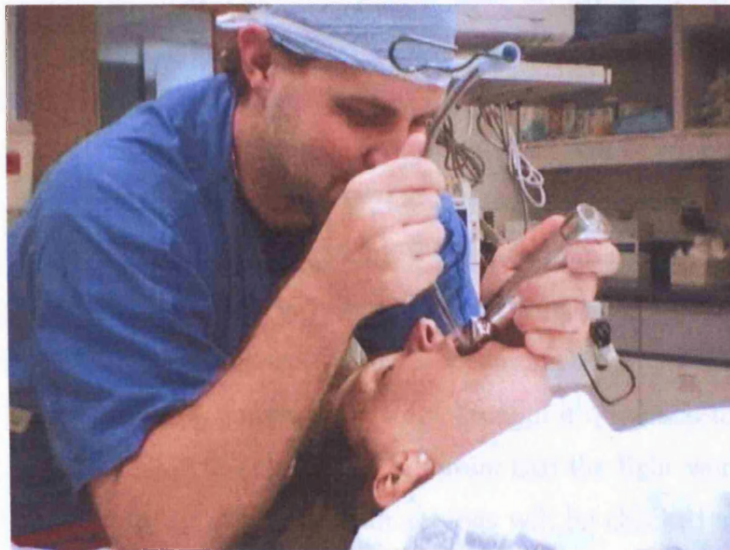
Assuming the patient has arrived with no forms of monitoring, such as happens with transfers from the general ward, unlike our case here, there is a general ordering of work. But as is often the case in intensive care as one visiting cardiac surgeon put it 'there is never an always and never a never' and so there is a structure or process which is generally adhered to, but circumstances may alter that, such as a rapid clinical deterioration. One of the first forms of monitoring a patient will receive is an oxygen saturation probe. This not only provides an indication of the amount of oxygen carried on a haemoglobin molecule and hence gives an indication of respiratory status, but provides a wave form and a numerical display of the heart rate. This is a kind of clothes peg with a wire that goes back to the monitor and is 'clipped' onto a patient's finger or toe. Smaller versions are also used, particularly with patients who have poor circulation which are clipped onto the ear lobe, or in some cases on the nose (naris). This is a familiar piece of equipment that is not just found within the ICU, what makes it slightly different is the waveform it displays, which reflects a blood pressure waveform. A blood pressure cuff is also placed around an arm (or occasionally leg), which gives a display in numerical form on the monitor and is set to measure blood pressure at a frequency inputted into the monitor by the nurse (and very occasionally, by a consultant anaesthetist/intensivist). Electrocardiogram electrodes are placed at three locations around the heart, providing another account of heart rate and additionally displaying a waveform of heart rhythm. This is attached to the body via three electrodes; a clear goo is in the centre of the electrode to aid in the transfer of an electrical current. This represents the electrical function of the heart. The admitting nurse, plus or minus a doctor will have a tactile and visual preliminary assessment of the body whilst 'sorting'.

Temperature will be measured using a tympanic (ear membrane) thermometer. The heat of the extremities however, particularly that of the feet will be assessed by hand as this gives an idea of how the heart and circulation are working. Hands or more commonly feet will be pressed by finger to see how long it takes for the blanched area to return to a normal colour, which gives an indication of hydration or dehydration (Capillary Refill Time) and will be assessed for warmth, another indicator of hydration status. The pupils will be tested for response using a pen torch and a pain response may well be tested as part of an assessment of consciousness level, what is known as the Glasgow Coma Score or GCS. If any of these are deranged to a level contrary to what would be expected then it may well mean other courses of action need to be taken. On another level what is happening, is the body is being made sense of; it is being rendered legible. Through some of the more basic techniques that are ubiquitous throughout the hospital, within the ICU they are part of the routinisation of the admission process. The routines are circumscribed in the observation ('obs') chart with each piece of the assessment having a particular place to be written or drawn or 'charted'. The admission forms and handover forms similarly require this information, so it is firmly sedimented as a particular intensive care practice. The body is beginning to be manipulated as a form of representation to fit the chart and the chart itself can be seen as a way in which the practices are ordered. Often changing the observation chart is used as a specific tool in order for changes in practice to become concretised (Chatterjee *et al.*, 2005).

Of course the patient will already have at the very least an oxygen mask attached via a face-mask, but they may or may not be unconscious at this point. If they are not, the likelihood is that they soon will be as this is one aspect of being 'sorted out'. If they do not already have venous access a cannula will be inserted in a peripheral vein by the doctor. Whilst some nurses can cannulate patients, during the admission process this is seen as a medical responsibility, although if more than one nurse is involved with the admission, they may well do so on instruction from the admitting nurse. The cannula is used at this point for the administration of anaesthetic drugs, resuscitation drugs or resuscitation fluids. As with the example of Elizabeth and the Registrar, an arterial line will also need to be inserted. This is a crucial piece of monitoring equipment for the intensive care team and in part signifies that the sick body is transferring into the realms of the critically ill body. It allows real time measurement

of blood pressure, and shows a waveform corresponding to blood pressure through the cardiac cycle on the monitor screen. In addition it allows direct arterial access from which to withdraw blood samples, most significantly the arterial blood gas which indicates the respiratory status of the patient in addition to key serum electrolyte and lactic acid (lactate) levels.

Without the arterial line intensive care work becomes extremely risky³. With the example of the lady who arrived from the emergency unit, she did not have an arterial line, so the first duty of the registrar was to insert one. She was trying to insert an arterial cannula in the radial artery, she had failed a few attempts on the other side of the patient so had gone to the opposite wrist. The patient was unconscious, sedated with a short acting sedative infusion and intubated receiving mechanical ventilation from the machine to the left of her head. Without an arterial line there is little hard evidence for deducing whether the form of ventilation is sufficient, so it is needed pretty soon. On occasion patients are intubated in the emergency unit by an anaesthetist, and in this case it was because the woman had stopped breathing as a result of the drugs (and alcohol) she had ingested. So immediate intubation was necessary and so she was brought up to intensive care without the arterial line.



Picture 6.3: Process of Endotracheal Intubation.

³ Although, as Sarah (one of the former Sister's quoted in Chapter Three) made clear with regard the oscilloscope, the numbers have only become significant since the technologies have become embedded within everyday practice, and these technologies did not exist when she was a new staff nurse which by the standards of the period of field work would be considered extremely risky.

Now that an arterial line has been inserted through the skin into an artery it is transduced with the monitor, giving an accurate measurement of blood pressure. So now an endotracheal tube will need to be passed in order to facilitate mechanical ventilation, which is one of the features of intensive care. As was discussed in the opening chapters this aspect of intensive care work has been seen as a defining feature of what constitutes intensive care, particularly as intensive care medicine as a professional group often defines itself as resulting from the Copenhagen polio epidemic. So for reasons of safety, an arterial line will be inserted prior to intubation in order to keep check on blood pressure and following intubation check the arterial blood gases (ABGs) to ensure that the body is being appropriately ventilated. A blood gas may also be taken if there is some uncertainty about whether the patient should be ventilated. This generally occurs between the admitting nurse and/or the nurse in charge and the medical staff, who will have undertaken their own assessments of the patient, or call upon others assessments (such as orders from the consultant intensivist who may not necessarily be physically present).

Through taking and analysing a sample of arterial blood, disputes over the appropriateness of intubation and ventilation are generally settled with the criteria for intubation being agreed between the two parties prior to the analysis. As noted previously, the anaesthetic drugs will be prepared in order to paralyse the body (patient) and sedated so that the person (mind) will have no memory or knowledge of the paralysis. An Ambu-bag with a tight fitting face-mask will be prepared, a high flow of oxygen will flow through it and it will be placed by the head of the patient. The endotracheal tube will be lubricated with KY jelly, and the pack which contains McGill's forceps, tapes for securing the tube and a form of suction called a Yankeur and a 10ml syringe will form the base for the procedure. The laryngoscope which allows visualisation of the vocal chords has a ridge through it on which the tube can be slid into the trachea. This will be checked to ensure that the light works and the blade (a curved ridge) is secure. The ventilator settings will be checked and the bed laid flat with the intensivist/anaesthetist located in the space behind the patient's head and the back wall (see picture 6.1) and the Yankeur attached to a vacuum pack will suck out any debris from the mouth and throat to ensure it isn't pushed into the lungs. A second doctor or nurse will administer the anaesthetic and a third member (the second doctor or nurse if available) of the team will squeeze the now paralysed

patient's throat to prevent gastric contents from coming up into the mouth (Sellick's manoeuvre).

At this point the patient will be completely paralysed and at the mercy of the intensive care staff, there are no spontaneous breaths being made. The first doctor at the head of the bed has lifted the patient's chin back whilst a firm mask is applied to their mouth and nose. The work of breathing is now being performed by that doctor, there may be a reduction in blood pressure but the issue now surrounds inserting and securing the tube that will create a circuit between the patient's lungs and the ventilator. A nasogastric (NG) tube will also be positioned so that feeding can commence as soon as possible. Once this is done and the patient is attached to the ventilator, the majority of the work of 'sorting out' an intensive care patient has been done. An arterial blood gas will be taken once the patient has safely been 'put' onto the ventilator, additional bloods will be taken as part of the admission process. A long suction catheter is then passed through a hole in the endotracheal tube by the doctor or nurse whilst the patient is on the ventilator. Suction will be applied to the catheter once it reaches a certain point in the lungs which will enable an assessment of the state of the lungs, through the sputum that is withdrawn, and ensure that gastric contents are not withdrawn which would suggest an oesophageal intubation. This is a risk associated with intubation whereby the ventilator (or hand of the nurse or doctor) would be ventilating the gastro-intestinal tract as opposed to the lungs. Of course an oesophageal intubation would be associated with a rapid deterioration in the respiratory and cardiovascular status of the patient, which would be noted and acted upon as it occurred, but it is part and parcel of the process and risk of intubation. A portable X ray will be ordered to ensure that the new tubes are in the correct position. Swabs will be taken from the body to ensure that should Methicillin Resistant Staphylococcus Aureus (MRSA) be present it can be treated. It also ensures that it did not come from intensive care, an accountability measure. As in the opening portion of field notes (focussing on Elizabeth and the transfer of a patient from the Emergency Unit), the malodorous body will need washing and a change of sheets will be necessary, irrespective of whether or not the patient had 'pee'd the bed' or not. The body may well need additional large venous access for particularly irritant drugs, such as those which increase the force of the heartbeat and over time the amount of equipment in the bed space may accumulate depending on how 'sick' the body is. The

body is now being rendered legible to intensive care staff. It is being made amenable to further treatment of the underlying disease (if appropriate) whilst wholly dependent upon the supportive technologies that sustain it, including the intensive care staff.

Once the patient, or more accurately the body, is 'sorted out', they are not only in an intensive care bed, but they are embedded into the technology that enters, sustains and surrounds the body. The body has been breached, but it has also been extended into the technologies that have been secured to the strictly corporeal body. The heart's own rate and rhythm is displayed on the monitor, the internal physiological processes are presented as external 'representations'. The body is now linked to the hospital through the network of piped medical gasses that 'connect' the lungs to the ventilator. Arteries are not only linked electronically to the monitor through a transducer, they are 'anastomosed' to a PVC circuit. A pressure bag of fluid squeezes continuous small amounts of saline to maintain patency of the arterial vessel and prevents the back flow of arterial blood within the circuit. Veins are infiltrated by numerous drugs and fluids. Feed comes in from another line to the new NG tube, whilst urethral urinary catheters and on occasion faecal management systems and NG tubes drain the body. Everything going in and coming out is meticulously measured and documented. The body has been manipulated, squeezed, injected, ejected, paralysed, forced and reduced to a mathematical representation of itself. The body is now simultaneously opened, closed, drained, filled and significantly it now makes 'intensive care sense', being rendered safe and legible by intensive care staff. The body has now become, both physically and metaphorically, an intrinsic part of the intensive care unit.

...if you em come into the bed area or something (.) very sick on intensive care you can come in you've got em you've got a filter in your bed area, you've got your monitor you've got your PiCCO box em all the connections to your PiCCO wire you might have an oscillator at the back of the bed which is thundering away and sounding like a washing machine on a spin dry cycle at the back so it's all you know so many things going on and it's as you get more used to it you just you forget that they're there you become less aware that it's in your face and you just em you can just em you can just you instead of staring intently at it you can pick up what's going on with everything you become em a bit more aware of any changes and any things that are going on around you.

(From interview with George, staff nurse)

George is a staff nurse with many years' experience; he worked in the High Dependency Unit (HDU) before the merger between the two units under the auspices of Comprehensive Critical Care (DoH, 2000) in 2002. He is referring to the Pulse induced Continuous Cardiac Output (PiCCO) monitor and a specific form of

mechanical ventilation called High Frequency Oscillatory Ventilation (referred to as the oscillator) which does not inflate and deflate the lungs like conventional ventilation but keeps the lungs open. A piston ensures that carbon dioxide removal and oxygen delivery occur through oscillation. But more importantly he is referring to becoming an intensive care nurse and being able to switch off from the technology, work with the technology without letting it take over his concentration, as can happen with junior nurses (as will be noted in the next section of this chapter). He can remain vigilant of the representations of the body in mathematical form through the monitoring equipment without being dependent upon it. Changes in condition are noted, he no longer stares intently at the technology. The difficulty for him when coming into intensive care was to see the person over the technology and being able to deal with the unconscious totally dependent patient, when he was familiar with the verbal and the conscious patient in HDU. Whilst recognising some of the issues concerning work in ICU, they themselves give rise to new ways of seeing:

you filter out the technology and you just see the important bits of it you know em rather than looking at er a ventilator and eh seeing em all the expiratory valves all the filters all the tubing everything else around it you just see the fact that your tidal volumes have dropped you know or em you know somebody's you know you look at the flow diagram on the front and you can see that somebody's starting to take a breath over the top or that your inspiratory pressures are rising or whatever

(From interview with George, staff nurse)

The technology performs an important function, but critically it is at the intersection between body and machine that intensive care staff can commence the work of filtering out that information. Information that is considered useful or useless is sequestered so that the work of intensive care can happen. The question remains over which information is filtered, what is not and how that is used or ignored, which will be reviewed later. Perhaps more tellingly it is through the technology that he gets to know the body better. Through the insertion of numerous lines, drains, tubes and numerous modes of monitoring and controlling the body can be understood or becomes legible. This legibility is further concretised in the way it becomes a fact when written onto the 'obs' chart and associated documentation. But this legibility is in part made possible through recourse to artefacts. The artefacts themselves become cultural artefacts through shared knowledge and understanding of the specific meanings they give forth. The body through these artefacts becomes legible to the staff of intensive care and become a shared ground through which the body can be discussed. The body itself becomes unreliable as a source of information on its own, it

is through flow diagrams that the most mundane yet most important things such as breathing are re-read. He can tell when the person (the body) is no longer paralysed as breaths are taken over those delivered by the ventilator and this demands a review of the ventilation. As the body has become joined to the intensive care unit, we can see from George's explanation of 'taking breaths' it is becoming increasingly difficult to separate out that which is bodily from that of the technology. Through these artefacts the work of reading the body becomes enmeshed in the reading of artefacts, the body is read in extension to these artefacts.

Consultant: I want somebody to do the bloods, x-ray, and sort out all the structural stuff. I want somebody else to go through the notes and get a thorough history I don't want you to just write down what I've been told, I want you to read back and find out.

(From field notes)

What information is considered reliable and what information should not be trusted is demonstrated by a consultant intensivist who had 'retrieved' a patient from another hospital. Even though the intensive care consultant has discussed this patient at length with the referring intensive care consultant, the facts he holds are not considered totally reliable. He has given an account of the patient to the junior doctors, but his account should not be paraphrased and written up in the medical notes. He demands a thorough history of the patient to be documented drawing from the notes supplied by the referring hospital. This is in part a history of the person, how they came to be in intensive care in the first place and what had happened to the body within the referring intensive care unit. In telling of the body, as we have seen, it is a tale of the organisation and practice of the referring ICU a tale of the embedded body that has been physically linked to another ICU. He expects a thorough assessment of the body, as he put it the 'structural stuff', the stuff that will form the foundation for any further treatment. He demands that the body be read and interpreted in a way that makes sense to the organisational idiosyncrasies of *this* intensive care. The equipment and scarification produced from the previous 'home' of this intensive care patient need to be documented, the old lines need to be removed and replaced with this intensive care units equipment. Their critically ill body needs to become 'our' critically ill body. Not that this means the previous intensive care unit is an inferior intensive care unit, more that the body needs to be processed or 'sorted out' in a very particular way so that the body can be presented as 'our new patient' on the consultants shift 'hand-over' Ward Round in a few hours time. For reasons of accountability the new ICU requires a

'clean slate' from which to work from, foreign equipment needs to be removed and replaced with the local equipment. Whilst the work of legibility has been done elsewhere, the body needs to be made locally legible, the 'sorting out' and documentation needs to be done in order for the body to be presented on the ensuing Ward Round legibly. The body is ceremonially incorporated into the organisation, physically and metaphorically.

The body is not completely bereft of meaning, as noted earlier in the process of sorting, tactile and visual assessments are being made, yet the legitimacy of such knowledge can be called into question. The PiCCO (Pulse Induced Continuous Cardiac Output) device mentioned by Sarah in Chapter Three and George earlier in this section has in some ways usurped the tactile measuring of the warmth of extremities through its provision of numbers. But on the other hand, direct measurement of blood pressure and the tactile assessment of hydration status can provide an occasion for such technologies. The differentiation rests upon notions of legitimacy, tactile assessment is a legitimate means through which such technologies can be brought into play, the numbers that the machine produces legitimate clinical action. However, it is through technologies of the tactile and the electronic that the body can be made to mean more. Through the process of sorting out the patient (the body) the body can be made to give a greater meaning. It is a process of 'sorting out' the body in order for it to be made more visible to intensive care staff. Once the process begins with the clipping of an oxygen saturation probe, the clinical body can begin to be judged. Different aspects of the body are required to tell their story about temperature, consciousness level, blood pressure and so on. The body is being manipulated so that it can give information about itself that can fit the format of the organisation as represented through the chart, and this in turn moves intensive care staff to order the body in a particular way.

In order to make sense of the body it needs to be punctured, entered and linked physically and metaphorically to the organisation. It receives from the space and expels into the space. This process is tied into a judgement of the body, it is required to give information about itself through interpretive monitoring equipment that are in turn interpreted and made sense of by the staff. Ideas of risk and uncertainty are assuaged by the monitoring practices and supportive therapeutics. The body is totally

vulnerable and pressures are exerted on the body, manually and mechanically in order for the body to be rendered legible to intensive care staff. So the body is sorted out by being assimilated into the fabric of intensive care, which makes it hard to separate out the points of the body and that of the technology (Place, 2000). As a consequence issues over factual and fictional arise which are settled by the intensive care staff. The ICU staff are vigilant to the changing nature of the body, but the body is transmogrified into a mathematical representation of itself which further enmeshes it to the technology. In essence the body is processed in order to make sense, a greater level of meaning than bodies can usually provide, the body has begun a process of assimilation, to be embedded within the structure of intensive care. Through 'sorting out', documentation and presentation of the body, it has been rendered legible to the local and specific intensive care unit.

(Re)Discovering the body.



Picture 6.4: Intensive Care Patient Prepared for Transfer.

For doctors and nurses within intensive care, the body is seldom mentioned in its own right, yet is frequently referred to or manipulated, controlled and made visible. Patients are referred to as patients, or between intensive care staff by the name of the nurse, such as 'Bob's patient', by their Christian names or by a form of address that has been agreed with the patient's family, which is generally a familiar name such as 'Chalky'. The 'body in the bed' is one of the few occasions when explicit reference to the 'body' is actually made. It is a term rarely used within intensive care, when it is used it is often as a term of admonishment, generally between nurses. It suggests that a poor quality of nursing care is being provided. To simply 'view the body' as simply a body does not fall into the professional mindset of the nurse, even though to work closely with the body is a large part of the physical labour of nursing. To some extent

this suggests a tacit implication that bodies are seen as separate from the rest of social life, we are not embodied beings as such (Zaner, 1985; Mol, 2002) and within clinical intensive care research (performed by clinicians) this is a taken for granted assumption. The nurse is supposed to practice in such a way as to transcend the simply biomedical or patho-physiological body, recognising other aspects such as the social, emotional and spiritual facets of human life (Watson, 1999). This, in part, is a recognition of nursing's separate identity or ontology from that of medicine. As such, it is of great significance to the intensive care nurse not to see her patient as a body, but 'know the patient' (Radwin, 1996) even in situations where the normal processes of interaction are made physically impossible due to anaesthesia. Body discourse such as the 'body in the bed' can also suggest that the nurse is relatively junior, when they are still trying to get to grips with the technologies that surround them, technologies that sustain 'their patient' whilst identifying with 'their own space'. In part this reliance on technology and the delegation of human characteristics of dealing with bodies, such as touch are relegated to a lower level of significance for the junior intensive care nurse (Estabrooks & Morse, 1992). One nurse in the ICU likened seeing or treating patients as the 'body in the bed' as a sign of her emotional break down as a consequence of work in intensive care:

Sal: it was coming to the end of the shift and you know those shifts where you just don't stop I mean it was a busy patient and that but I was speaking to Charlotte [nurse in charge] and I realised I had no idea what my patient was called you know I'd been working on him all day and I had absolutely no idea who it was

Paul: that's awful

Sal: I was absolutely devastated and that was when I realised I was burnt out and had to get out of the unit so that's when I left and went to work in the nursing agency.

(From interview with Sal, Senior Staff Nurse)

To refer simply to the body as opposed to the whole person within intensive care is generally seen in a wholly negative light. When nursing and medical staff do this they are often challenged even though it is a frequent occurrence in relation to individual bodily pathology. That is, whilst the patient is often reduced to the individual pathology or reason for admission as previously highlighted, the patient should not be explicitly referred to as a 'body'. In part this 'reading pathology' can be seen to make sense for intensive care staff as a level of communication between professionals involved in similar work. It adds an element of recognisability acting as a 'shorthand' reference to a particular patient. It is a normalising gaze in which having learned to view the body in a certain way, this becomes what the critically ill body actually is. In

discussing experiences of work it allows shared understanding between the intensive care staff, a sort of *aide memoir* of shared experiences, of doing member:

SHO: *You know her don't you, previous thrombosis, small bowel resection, em again in the x-rays which we did this morning, em, you know the contrast is only going to the anastomosis, and stopping at the anastomosis.*

SpR2: Yeah.

(From ward round)

'...you know the 'Triple A' that had his femoral artery ruptured downstairs...'

(From field notes)

Whilst there is little explicit reference to the body within intensive care, the body itself can make itself visible. Aside from those visualising technologies already noted, the body itself leaks, defecates, oozes and calls attention to itself in spite of anaesthesia. Those mundane features of bodily life that are generally obscured or hidden for reasons of decency or taboo within normal social life are brought to the fore within intensive care. It was not uncommon to witness intensive care staff referring to the unit as a farmyard, particularly as the unconscious cannot visit the lavatory even if there was a patient lavatory within the intensive care unit, which there isn't. Close contact with bodies and their excreta are part and parcel of daily life in intensive care. Bodily needs of the unconscious are the same as the conscious only there is no facility for the unconscious to do anything about it. To a large extent the technologies in ICU are themselves strategies to negotiate the restrictions imposed by other ICU technologies. Perhaps the most significant is the ventilator that performs the work of breathing among the paralysed unconscious patient. It requires a circuit between the technology and the body, the point at which it connects or intersects with the body is either the mouth, the nose (which is rare) or a direct puncture through the throat (a tracheostomy).

The other technologies, such as feeding tubes, intravenous lines, endotracheal suction devices are made necessary due to the limitations imposed by ventilatory technology. Urinary catheters and faecal collection systems on the other hand are necessary in part as a result of ventilatory technology, that of immobility but more significantly as a result of unconsciousness. Whilst those bodies that are paralysed and sedated require mechanical ventilation, those that are mechanically ventilated do not require paralysis and sedation. Urinary volume measurement and timing of defaecation therefore require measurement to prevent other issues from arising. Urine volume is checked

every hour to guard against renal failure and to ensure that the patient has sufficient cardiac output (in addition to the more technological methods of measuring such output, as previously noted). Point of last defaecation is noted to ensure constipation does not occur among the unconscious. On the other hand fluid loss can be measured using faecal management systems, which may often be associated with antibiotic use, another example of technologies being used to counteract the effect of other technologies. But what these leaks and soiling processes do is refocus the attention of the nurse in particular to matters of the body, as issues surrounding the body are recorded hourly (except, for the most part, with regard to faecal matter) allowing a close observation of bodily stuff. The focus of observation of the body is generally confined to that which can be made legible, that is written onto the chart. Even outside of the routinised, heavily structured nurses' shift, the body can make itself noticed as in the example of a patient anaesthetised during transfer between a District General Hospital ICU in a nearby city and the regional ICU:

The consultant is sat behind Kevin's [the patient] head and holds his hand, supporting it so as not to disturb the infusion during the transfer. 'Blues and Two's' as the ambulance speeds onto the motorway...He talks over Kevin to Daisy [the staff nurse] who is sat in line with Kevin's right arm. He is talking about his son. There is some oozing of blood from the line in the right side of the patient's neck, which lands on the consultant's arm, who stares at it, unable to clean it off. The patient remains motionless, with no obvious movement, strapped into a 'Rugged' stretcher, sedated and paralysed.

(Retrospective notes of inter-hospital transfer)

Sometimes it is through the more subtle aspects of intensive care work that the body makes itself visible. I am not suggesting that the unconscious body makes a conscious effort to make itself known. Rather, through those leaks from the body, the intensive care staff comes to regard the body in a slightly different way. Through the process of sorting out the body, making it hyper-real it becomes sanitised through the ways in which it is re-presented on a digital display and through its (re)translation (Callon, 1986; Latour, 1987) into colour coded words, numbers and symbols on the 'obs chart'. Through the leaks and excrement the unsanitised, carnal, fleshy body is recognised, the mundane everyday actions which in normal social life are concealed are made visible within intensive care through faecal or urinary bags. It is this bodily work that is seen by some intensive care staff as the heart of what the intensive care nurse is about, reminiscent of Florence Nightingale's musings about the body and the spatial (Nightingale, 1860). Yet through the leak of blood onto the consultant's arm the body is made present. The arm cannot be moved away from the ooze easily, the

consultant just has to sit and watch the ooze of blood from the neck of Kevin drip onto his arm. The line acts as an entry point into Kevin's body, yet through this, if even for a moment, the body of Kevin is made visible to the consultant who has no choice but to remain motionless. However, through reading the leak from catheter which has been passed into the internal jugular vein, the consultant recognises that a new line will probably need to be re-sited. He is already justified in having the catheter re-sited, but will have the medical notes checked to affirm the length of time the line has been in (as he asked the junior doctors to check in the previous section of this chapter).

Junior doctors (Senior House Officers) are required to spend six months within intensive care as part of generalist training in medicine or surgery. Prior to their rotation into intensive care they have spent at least eighteen months practicing medicine within medicine and surgery. Often they will have two or three years experience of work within the hospital prior to their emersion into intensive care. As a consequence, they have developed certain ways of working and practicing medicine which are not necessarily congruent with the idiosyncratic way in which medicine is practiced within intensive care. Relations with nursing staff are wholly different to that they will have encountered on a general ward and it has not been unheard of for intensive care nurses to be accused of bullying. This is a wider issue which will be discussed in greater detail in a subsequent chapter. However, they have particular relations and ways of seeing bodies that have to alter for them to function effectively within intensive care.

The ways in which the bodies of the critically ill are assessed within intensive care, particularly respiratory assessment is quite different to that which junior doctors will be familiar with. To a large extent this is down to the reliance of the body upon a mechanical ventilator that performs the work of breathing for them, something that is peculiar in form to the intensive care area and in (although as anaesthetic machines they appear as where, such as the Operating Theatre and Emergency Department). As an example taken from the field work, a junior doctor entered the 'nurses' bed space' and began an assessment of 'her' patient. He asked the nurse to help him sit the patient up so that he could assess the chest. The nurse responded, "you're joking aren't you" and the doctor explained the gross anatomy of the lungs to the nurse and

the importance of listening to the posterior surfaces owing to the larger surface area. The nurse, who did not seem too pleased about receiving an anatomy lecture from the junior doctor explained that the patient was unconscious, receiving mechanical ventilation and to sit the patient up would risk dislodging the endotracheal tube, and followed up with “are you an anaesthetist then?”. The junior doctor responded that he wasn’t, but he had been asked by the registrar to ‘assess ‘the patient and write it up in the notes and how could he do that if he couldn’t properly assess the lung fields. Whilst under normal circumstances the doctor’s action would be the right way to assess the patient’s chest, within intensive care, this is seen as unnecessary as the noises which are heard in the lungs are so much louder owing to the form of ventilation. It is accepted practice to listen to the front of the chest and as much of the posterior as possible without moving the patient. The doctor left the bed area and came back with the nurse in charge, who informed him that he could sit the patient up if he felt it was necessary, but should consider speaking to the advanced trainee or consultant intensivist about it first. So he continued the assessment as best he could and wrote up his assessment in the notes. On the evening ward round he was complimented by the intensivist on his thorough history. He replied that he was unable to perform an adequate assessment of the chest as the nurses would not help him sit the patient up. “Quite right” the intensivist replied, “I think we know enough about this patient’s respiratory status without messing about with him, don’t you”, and the ward round continued its march around the unit.

On the one hand this is one of those stories that nurses enjoy as they have a small piece of victory. They have an impression of who this doctor is on account of his ‘cocky’ behaviour and the tale will be retold the next time anybody has an issue with this particular junior doctor. Invoking senior medical staff is a means through which the nurses are ‘doing member’ on account of the close working relationships built up over many years they have had with them. However, the consultant is then left in a position whereby he cannot criticise the nurses, and can’t be overly critical of his or her fledgling rotational doctors either. What perhaps is of greater significance is how intensive care staff are compelled to read the body. Whilst the fundamental knowledges of anatomy, physiology and patho-physiology remain the same, the way things are done are slightly different and are made so through the contingencies of the technology. It is not just that the technology moves staff around the body in a

different way, the body has to be regarded differently as a consequence of the technology. As previously noted the body and the technology become inseparable, the body is intrinsically linked to the fabric of whatever it is that constitutes intensive care. The old rules no longer work here and among the figures, numbers and quantifiable readings of the body, the way that the body is approached regarded and assessed is altered too and there are processes and technologies in place, such as the nurses and other intensive care staff themselves, that ensure that the body is regarded in its own specific way. The body needs to make intensive care sense, but there needs to be in place a technology that ensures that the body is read in an intensive care way. But sometimes even this alters; the way that the readings of the body can be read can be drastically altered by some of the tools that regulate the ways in which intensive care staff practice.

The body of persons?

Nicola the registrar is inspecting the observation chart, a large piece of documentation on which nurses record physiological variables, colloquially known as the 'obs chart'. She is interrupted by the appearance of a staff nurse, requesting her to see a patient on the other side of the unit who had been transferred from the Cardiac ICU a number of days ago. "Which one is he" Nicola asks, "he's the chap that came over from cardiac" [Cardiothoracic ICU], replies the staff nurse, "Oh, heart block man" states Nicola. Rosy and John start laughing as Nicola leaves her investigation of the chart to take a look at 'heart block man'.

(From field notes)

During the ward round, patients were referred to by the medical staff by their surnames, or in relation to a particularly problematic aspect of their pathology. The ICU had instituted a restricted visiting policy in order to prevent family members being present during the round. This had a variety of benefits for the medical staff within intensive care which will be discussed in the following chapter, suffice to say its rationale was couched within a discourse of privacy and confidentiality for the patient. So between 10:00 and 12:30 every day, intensive care was bereft of visitors. During this time, the usual practice of referring to patients in passing continued, the weekend handover round (at about 17:00) and to some extent the night round (21:00) saw family members or visitors present. For the most part, this meant that patients were referred to by their title and surnames as opposed to pathology. However, at particular points Christian names are used. This is a fairly rare occurrence that occurs specifically when either discussing with close family members about withdrawal of treatment or when a long term patient is awake and able to communicate (but not

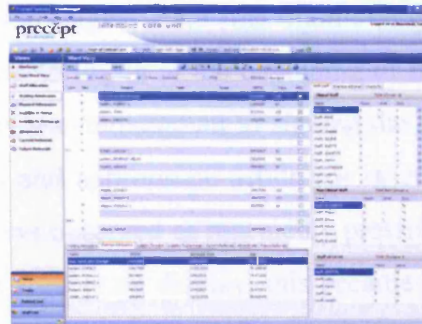
necessarily able to speak). For the most part engaging within discourses of pathology (such as ‘heart block man’ from the above section of field notes) and their route of admission (‘the chap that came over from cardiac’) and treatment such as the ‘oscillated patient’, or the mistakes of others (‘ruptured artery from downstairs’). Yet when intensive care is seen to fail, then the discourse alters to that of palliation which requires involvement or discourses of the body as person.

Victoria, one of the intensive care Sisters, recalled a story of looking after a well dressed man who came up from casualty. She admitted him as an unconscious patient and allocated herself to look after him when she was on shift. Stripped of any identifiable features within intensive care, she regarded him in relation to the way he came in; with clean tidy hair, shirt and tie, and so forth which to her symbolised somebody of a certain social status. He was single and had few visitors, which did not give her any ideas about who this man actually was either. So she pictured him as “a polite well spoken gentleman”, somebody reminiscent of her English middle class grandfather. As he woke up, he ‘mouthed’ please and thank you which affirmed her belief that he was polite and by implication, well spoken.

When the gentleman was actually extubated a few days later, she went across to him and introduced herself as the nurse who had been looking after him for the past few days. He replied in a thick local ‘working class’ accent, to which she was particularly shocked. She explained that she had come to regard him in a certain way for all that time she had been with him and there was no indication to assume otherwise and to hear him talk with such an accent completely threw her. Her account is a moral tale in some respects, but it also emphasises how focussed upon the body intensive staff become and how difficult it is to regard the body as a person. Bringing ideas of personhood into the equation to some extent involves making moral judgements upon persons. As mentioned in the previous section of this chapter, a moral judgement is made dependent upon mode of admission, pathology and so on, when these are benign and have no moral underpinnings, such as this gentleman who was admitted during the winter with a severe chest infection, there is little basis for these judgements to be made. Given the materials and cultural artefacts that are available to intensive care staff an idea of personhood is drawn from this limitation of available materials (Hacking, 2000). The intensive care gaze requires that patients are judged in

certain ways, in part they become the way they are seen through a normative and normalising judgement, but on occasion, the way the body is viewed and the way that view is legitimated can be made painfully obvious that it does not always work in the way the staff would anticipate.

Bodies lost in translation.



Picture 6.5 Example of Chart

The charts used within intensive care have comprehensive spaces for a wide range of information about critically ill bodies to be placed in them. It is split in to two main sections in which fluid balance status or vital signs are measured. Each hour the nurse details ventilation settings, the mode of ventilation, the volume of inspired and expired breaths (Tidal Volume), respiratory rate and oxygen saturation levels. Temperature and consciousness levels are measured every three to four hours unless the body has a particular pathology that would warrant more regular monitoring such as malignant hyperthermia or a neurological or neurosurgical issue. The concentration of inotropic drugs which increase the contractility of the heart and in some cases constrict the vessels (notably the administration of noradrenaline) in order to maintain a given blood pressure are measured in micrograms (of drug), per kilogram (of body), per minute and are titrated against the mean arterial blood pressure which is recorded on the 'vital signs' side of the chart. The syringes are checked each hour and documented on the 'fluid side' of the chart alongside the rate (which usually appears in red to suggest that it is not a deliverable figure), which protects against over or under delivery of a given drug. Specific coding strategies are employed which new staff take a few months to get to grips with and which generally confuses the majority of the medical staff.

Aiming toward a paperless intensive care unit (largely introduced by a particular intensive care consultant), a move was made to dispense with the paper chart through the introduction of a computerised nursing observation management system (an example screen shot of such a package can be found at the beginning of this section. This, in part, was a means through which the medical staff could exercise more direct analysis of the chart and recall information more readily for audit purposes. Some of the specificities of this will be discussed in Chapter Nine. The new system automatically recorded vital signs from the monitoring equipment and simply required the nurse, who had to log in at the beginning of the shift, to verify that the numbers were correct. This was tantamount to signing the program to verify that the vital signs had been noted and appropriate action (or inaction) had been performed. Although in practice this was observed as repeatedly pressing the enter key with little attention being paid to the figures on display, this became the new system of 'doing the obs', unless the physiological variables measured fell out of the 'normal range' (which was specified by the nurse) and some action was taken. However, it did not take long for nurses to find short-cuts and ways of amending erroneous observations. When asked about this, the nurses stated that they observed the monitor and were involved with the continual assessment of the patient, so the computer was the least of their concerns. The system became an object of scorn and ridicule, an audit machine which existed simply to get in the way of the proper work of nursing, that of dealing with the critically ill body.

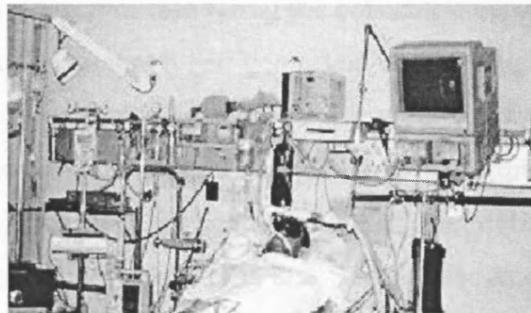
George: I had done em a couple of shifts over on intensive care em as part of em post-registration diploma courses em. So I had some experience only brief experience of the pre-computer system on ITU but um they took advantage of the amalgamation as a chance to implement the computerised observation charts and everything and em record system and em kind of eh well ward round partly some of the ward round notes some of the doctors do the ward round notes on there and er the nursing er report on there and they also introduced em the new the new filters as well, haemofilters at the same time so em it was you see you know their was a lot of change for me but it there was change for everybody else on ITU as well because they had to get used to that so. I wasn't aware of it before so it's just there. Some of the bed areas em due to like physical constraints, there just isn't room to get the computer [eh]
Paul: [Yeah]

George: Into the bedside so they still have the full chart system and everything there so it's still kinda swapping and changing between the two but I've never known any different other than the computer so its just been, just been there for me from the start really over on ICU

(From interview with George, staff nurse)

The system also enabled the consultants to record the ward round on the computer that could be retrieved at a later date. However, certain spaces which were available on the chart, such as for inotropic medication were unavailable on the computerised

system, the fluid side of the chart remained on paper and as a result both forms of documentation were in force at the same time. The established staff, particularly the nurses felt that having the two systems (when one system was perfectly adequate and had been for many years) disrupted the important work of observing and treating the body (the patient). For newer members of staff, such as George who had come to intensive care as part of the amalgamation with the High Dependency Unit, it was a natural part of having to learn the work of being an intensive care nurse. After two years with both systems in place, the computerised system was finally abandoned. The computers needed replacing as they were prone to crashing and it required two part time intensive care nurses skilled in information technology to ensure that they were working all the time, which took them away from their clinical responsibilities.



Picture 6.6: 'Old Fashioned' Intensive Care Bed Area with Patient.

Indeed the physical space constraints as George noted, required the computers to be placed angled away from the patient just to side of the bed space (out of shot in the picture above). The computer itself required a focus upon the screen now for the hourly work to be done. However, only half of the information required was available on the computer screen so the workload of the nurse increased in order to fulfil the requirements of both the computer and the paper chart. Whilst George found it quite easy to slip into this mode of working as the whole thing was about learning to be an intensive care nurse, established nursing staff found it a particular problem. This was more acute if they were not computer literate, predominantly the older staff members. The established staff found that their line of vision was taken away from the patient. Whereas before the focus was the monitor which was located at the head end of the bed and positioned slightly to the side of, or above the patient's head (the general position of the monitor is illustrated in the top right hand corner of the picture above), now their gaze was taken elsewhere, to the spaces between patient's. When inputting

or checking 'data' on the screen as opposed to 'obs' on a chart the computer screen demanded concentration upon it. The gaze became that of the computer over the more important gaze over the body. This was emphasised by Rachel a senior staff nurse with many years intensive care experience:

'the thing about these computers is that I spend so much time staring at the feckin' screen the patient could be doing cartwheels for all I knew'

(From field notes)

Significantly, the technology moved nurses to regard the body in a slightly different way (an issue that will be returned to in Chapter Nine). The space of the gaze had altered which had broader implications for how the body was regarded. When the paper charts finally returned (not that they had gone away (disposed of), they were always present in the dual charting system), they were regarded in a slightly different way. The extreme importance of measuring the concentration of inotropic support had gone when the space to document it had gone. The way in which the body was viewed by the nurse had altered slightly, which had direct implications on how the nurses practiced. Now the documentation and calculation of inotropic drugs had been lost. For some the ability to work out the concentration of drug delivered had to be taught, under the computerised system there was less of a need to know how to do it and if there was a need there was no space for it anyway. Interestingly, this calculation and documentation was lost on return to the paper chart by both established staff and those weaned into intensive care work through the computerised system. When the information was called upon, particularly during the Ward Round, it required frantic calculations of drug dosage, concentration, rate and volume. Some consultants (such as the one who had pushed forward the idea of the paperless ICU) made judgements about the nurses' (particularly new members of staff) competence, as they were not performing these calculations any more. Since new staff found the calculations particularly problematic (it was previously taught by their mentor in the first two weeks in the unit, but became glossed over as it wasn't in constant use) a whole new programme of assessing competence was developed. This was much like developing new technologies to counteract the effects of other technologies, as was discussed in the opening part of the chapter in relation to mechanical ventilation. Indeed for many new nurses what was no longer emphasised was the therapeutic range of the drug that meant that patients could be receiving a far larger dose of drug (rather than a far lower

dose) than would be therapeutically necessary (there is an upper limit beyond which the efficacy of the drug plateaus – the therapeutic index).

It is not just the issue that something had been lost in translation between paper, paperless and return to the paper intensive care unit, although this is significant in its own way. What the computerised system did, to emphasise Rachel's quote from the field notes, is legitimate a looking away from the body. Whereas before the nurse was physically linked to a particular space and was forced to regard the body in a particular way. The computerised system legitimated a turning away from the body, an ability to disregard the body. However, in practice the effects were lessened as the power of the paper chart forced the nurse to look upon the body of the unconscious. On the other hand practices such as measuring capillary refill time, which was a requirement of the computerised system and required the physical contact with the extremities of the critically ill body to measure the time of refill and assess the temperature of the extremities remained after the computerised system had been disbanded. Now it became a part of the way in which the nurse assessed hydration status and was later enforced through a particular 'care planning' chart which was completed at the commencement and termination of each shift. So, the way that the body is regarded is shaped through the technologies such as paper or computer screen. They call upon the nurse to view and practice in a certain way that has implications on how the body is regarded and in turn made legible.

Sometimes what was intended to happen, the expected outcomes, did not in fact occur like that in practice. Something happened between the idea of what can be achieved and the actual performance of that achievement. Whilst those involved in setting up and designing paperless electronic information systems have a distinct knowledge of exactly what they wish to achieve (and market accordingly). How this actually works in practice remains a different matter. The unintended consequences and the mobilisation of a distinct set of technologies that influence the way that practice is conducted, alter clinical practices in ways that were not previously envisaged (see Heath & Luff, 2000). The way work is conducted in intensive care may be transformed in certain ways according to the rhetoric of software companies (and how this in turn is bought into by the consultants – they paid for the computer programs but received 14 free computers), yet the transformation of practice may be read quite

differently. Certainly there are things happening as a result of the technology, it calls the nurse to input details away from a mode of working which has been built up over several years of experience. Its relative simplicity to use is offset by the fact that the patient somehow gets lost among the entering of data as the computer cannot be housed in a position at the foot of the bed (where the original charts lay), so the point of observation of the patient has changed which not only alters the way in which practice is conducted, but limits the format of the data entry to that which is required by the program (Benson & Hughes, 1991) as opposed to that required by the health care practitioner. This in turn has implications upon the ways that the body is viewed within intensive care. The practical limitations of the technology and 'gaze' over the body are altered and this alteration is in part legitimated through the ways that technology moves the intensive care staff. In many respects, aspects of the body as recognised by intensive care staff through the application of new technologies became lost in translation. The way the body was made legible needed to be transformed to fit the format of the new program (Benson & Hughes, 1991), a program that appeared to fail to take into consideration the ways that intensive care staff (in particular nurses) practice, altering the way in which they rendered the body legible.

Summary.

Having set out to give an idea of the multiple spaces of intensive care and a thick description of the space of intensive care an analysis of working through bureaucratic systems was made in relation to gaining ethical approval (Chapter Five). Whilst some aspects of gaining ethical approval, and more significantly questions concerning moral judgements have been presented. This chapter has been concerned with how unconscious bodies are viewed by intensive care staff. Within this chapter, a broad range of ideas about reading the body has been presented, whilst illustrating the initial 'career' trajectory (Goffman, 1961) of the critically ill. The discourses of intensive care staff, as well as that of ethnographers (Place, 2000; Atkinson, 1995), are concerned with making representations of the body. However, there appears to be more at stake than a simple representation, the representation comes to be the way the body is in fact seen. The multiple readings of the body come into play through relations of extension (Strathern, 2004) to cultural materials around the body that are read in a specific way that produces cultural artefacts that themselves become the

legitimate reading of the body (Hacking, 2000). This is in relation to multiple processes of reading, or in Latourian terms a cascade of inscriptions (Latour, 1987) and this is what I intend to unpick for this summary.

Getting into intensive care is not necessarily an easy thing to do, as one of the intensivists on 'border patrol' to the unit demonstrated. There are particular ways through which a consultant from outside the intensive care unit ensures that 'his' or 'her' patient gains timely admission. Whilst there is a booking process whereby a junior surgeon will detail the name, age, diagnosis and proposed treatment, from which the intensive care staff judge how appropriate the candidate is for intensive care, the focus has been on the body and the unconscious body in particular; hence its omission from the main text. Suffice to say, other strategies such as turning up *en masse* with an obviously critically ill body, does not necessarily grant you access rights. The intensivist requires that the team who have just arrived traverse the appropriate path to admission. The intensive care consultant is aware that the patient requires surgery, not intensive care and so can stall the patient, dispose of them to their proper place until the patient is a legitimate intensive care patient. The body (and in this case the patient's brain) needs to have pressure released and only then will the patient become an appropriate admission, once the underlying problem has been treated surgically. The risk of admission for the intensive care consultant is that the neurosurgeon can stall surgery until 'he' the neurosurgeon is ready. Whilst for intensive care staff, there is little therapeutically that can be done until after the surgery, so dismissal is in part a strategy to ensure prompt treatment.

On the one hand this 'stalling' can be viewed as a means through which the most appropriate treatment is ensured. On the other hand, it can demonstrate the unequal power relations between the medical and nursing staff of a neighbouring city's District General Hospital and their ability to 'traverse' a particular system of admission into intensive care, thereby forcing the transferring team to wait in the operating theatre and dismissing the patient from the doors of intensive care unit. This is something that the intensivist can legitimately do. But more than this, it is something the intensive care consultant must do in order to maintain control over admission and discharge (a historical issue as presented within Chapter Three). The transferring team did not play by the rules in the game of securing admission to

intensive care. Similarly I didn't necessarily play by the rules of successfully securing ethical approval (as presented in Chapter Five). The penalties for not playing by the rules are that of waiting, in my case 23 months, in the case of the transferring team little over an hour until they could 'hand the patient over' to the neurosurgical and anaesthetic team. Suffice to say, time penalties came into play, in part as retribution for not following the established procedure. Whilst at the same time it reinforces the uneven power relations between those moved and made to wait and those who dictate the period of waiting (Adam, 1990; Frankenberg, 1992). In some way this could be viewed as a punitive measure that ensures the rules of the game are adhered to, at least, if waiting and by implication time can be taken from others then the most powerful, or those who are more powerful in relation to requirements of the other can dictate the length of time spent waiting. Through waiting, time becomes commodified, a commodification of time that can be taken at the expense of the errant transfer team or ethical approval applicant, and one that has punitive implications.

Once the patient arrives into intensive care and is transferred into the bed, specific processes of ordering and manipulation of the body are made. Colloquially, this is referred to as 'sorting out' and can only be accomplished properly once the body is in its appropriate space, the bed space. Without location in the bed, specifically the intensive care bed, it is rare for any supportive therapies to be instigated. This particular space is organised so that the work of intensive care can be done effectively and efficiently. Technologies such as the mechanical ventilator, the monitoring equipment, the work tops and syringe drivers are located so that they can be connected easily to the body. The body is forced to adapt to the technologies of its new surroundings. It becomes literally and metaphorically 'plugged in' to its surroundings through the insertion of adapters, such as numerous cannulae (intra-arterial, intra-venous and so on). The intensive care unit is not a space which has much dealing with patients wants or needs, as their want or need is to get through a period of critical illness alive, every other facet is rendered secondary to that goal. More specifically for intensive care staff, the objective is for the patient to be discharged from the ICU to the HDU, or since the merger of the two units, the objective became to transfer them back to a general ward. Once in the space, the work of transforming the body from that of the sick, to that of the critically ill can begin (Place, 2000). This is not to say that the body was not critically ill before, more that

little treatment work of the critically ill body can be undertaken until it is in its rightful place and the preliminary work of sorting out has been completed. The body needs to be physically, organisationally, metaphorically and as will be demonstrated, culturally embedded into intensive care. At this point, once the body has been rendered legible, meaningful and stable, can the work of treating the critically ill body occur. The body is forced to fit the space of intensive care and a host of adaptors ensure that this is made possible.

This space, however, is not a free space, when called to account the space belongs to the nurse, as opposed to the patient. However, the body of the patient is ultimately bound to the intensive care consultants, they accept and reject admissions (on the odd occasions when nurses have accepted admissions some of the consultants 'jokingly' referred to the nurse as a new intensive care consultant) and have responsibility for the treatments and procedures undertaken, particularly if they go wrong. Whilst between nurses and doctors the patient is referred to as 'belonging' to the nurse, should anything go awry then the patient resumes its position of being the consultant's patient. So the nurse has a bed area, a patient (for the most part), but the patient is just left with the bed. This is in part the area that the leaky, fleshy, carnal and sometimes polluting and polluted body inhabits (an issue that will reappear). The site whereby the stuff of the body is ordinarily hidden or sanitised, this becomes their space. As much as possible the body is silenced through methods of intubation and mechanical ventilation, as will be highlighted in the following chapter. Suffice to say, the body has been moulded to fit the requirements of the intensive care staff and the technology that now sustains them.

So, the critically body has been rendered visible through recourse to the monitoring equipment and those adaptors which make the body visible for recording and legible for sense to be made of those records. A position is produced from which the body can be read and this reading of the body is taken as a specific cultural artefact from those materials, such as the adaptors and monitoring equipment. For this to happen it has to 'embedded' within a particular space. However, these physiological representations of the body are not all that is occurring here; moral readings from source of admission, bodily location of injury, the particular pathologies, their home address, or the site at which the injury take place all help constitute a representation of

the body and of personhood. In no small way a moral judgement is made upon the personhood. To invoke personhood is to make a moral judgement upon the body, and this happens in the way that intensive care staff make sense of the body. However, the body itself is not morally neutral; it gives indications of personhood through extension to all these other understandings, an issue that will be picked up again in the following chapter.

These moral accounts of the body do not actively impact upon the physical treatment of the body, however, the attitude toward the body may change as a result of some of these knowledges about the body gathered through extension to issues surrounding that body. The technology in part legitimates a looking away from the body and this occurs across cases; however, it is made particularly clear to some intensive care staff how it alters the way they perceive as illustrated through new monitoring and recording technologies. The impact this has on how intensive care staff perform their work is illustrated through certain aspects of intensive care work being lost in the translations between paper charts, computer screens and the return to the paper chart. The technologies themselves become embedded within the technologies which sustain, the ventilator which displays so many variables about the work of breathing is viewed as bodily and some of the former boundaries between the body and technology become blurred through their inter-dependence. These modes of working, of seeing and doing, demonstrate a particular strength of alignment that when breached, such as by the junior doctor have implications for the integrity of how intensive care staff perceive their own role and the importance of their work. The following chapter, drawing upon these antagonisms between the body and machine, moral bodies, leaky bodies will focus on one particular anatomical site, that of the mouth. In so doing it will help illustrate some of the ambivalences present within the intensive care unit within a singular private yet deeply social space. The aim is to develop further critical insights into things bodily and some of the social accomplishments achieved within the intensive care unit.

Chapter Seven.

On Breaching Orality: a tale of two 'funny old men'.

Introduction.

Chapter Three briefly introduced some of the ideas surrounding intensive care within social life through the media and popular literary representations. It examined historical developments that have led to the rise of the intensive care unit in relation to specific sites, technological developments and a means through which specific practices are organised. In particular, anaesthesia has been presented as a specific site for the practice and development of a sub-speciality, intensive care, and later a speciality in its own right. Intensive care medicine is a speciality which has expanded through the hospital, incorporating other parts of hospital work, ensuring that a particular clinical space is available with little interference from other specialities of medicine (Carmel, 2006). In some way it assuages some of the risks associated with complex surgery and is a site in which the 'sickest' of the hospital population who have a possibility for recovery can receive intensive treatment. This provided a platform from which an examination could be made of the place of intensive care within contemporary culture. As has been demonstrated, intensive care is located in a space of the most serious issues; that of life and death; it involves the stuff of mortality; of a temporally static space. This serious stuff is recognised through these accounts as being on the verge of something, of liminality (Turner, 1970) and is used as a metaphor for serious political or economic situations that require an investment of time and attention. Intensive care becomes a spatial metaphor for everything and nothing, of everything to gain and everything to lose, a final opportunity, a finality come what may.

Chapter Two then focussed on the physical space of intensive care, how it is structured and set out, a thick description of the space itself. This space, from the corridor on the way in which has ambiguous meanings stemming from the adjacent paediatric intensive care unit. Signs abound, moving those who enter to act in a certain way. Warnings and instructions litter the space at the reception desk where you are reminded to 'wash your hands', 'ring the bell', 'speak to a nurse before entry', and 'leave at a certain time'. Even before the space is reached you are being

moved in certain ways to regard the space as a space of serious stuff. Once entered, the space is clean, if sometimes foul smelling, bright lights are all around with computer screens lit up around the space as though it was Christmas. The space is an altar to modernity, whereby quiet is expected and more signs inform you that intensive care patients need their rest. Having a metaphor of all seriousness, of finality, the space is buzzing with people, noises from machinery, chatter, laughter, tears, a lone radio plays to itself, doors slam. Yet the patients who inhabit particular designated spaces remain quiet, they are a fundamental part of, yet somewhat detached from what goes on around them. Whilst the ICU can be viewed as 'an altar to modernity' in relation to the technologies which inhabit the space, the space does not have the hushed reverence of a place of worship⁴. It is a space whereby medical technology can be worshipped, yet it is only the patients who are hushed in a state of forced reverence to the space by virtue of the life sustaining technology.

For Chapter Five, a completely different issue was invoked, that of gaining access to the site to perform the research in the first instance. In part this dealt with issues concerning silencing, of gate-keeping and preventing certain voices from being heard. The intensive care experiences of a single panel member within the LREC had a profound impact upon how the study was viewed by the members and ensured that unanimity was not secured until the point at which the majority of the thesis should have been written up. As the mother of a girl within intensive care, the onus was on the panel members to take notice of her 'real' experiences of intensive care. Of course, this meant reading intensive care patients as 'socially dead', meaning any alternate examination of the experiences of the critically ill at a time of vulnerability could not be morally reconciled. Because the intensive care patient, in her view, has no memory and by implication experience of being critically ill, any recall would come from what the post intensive care patient had received from family members. In her view this meant that the only legitimate people to be interviewed would be family members, who themselves are too stressed to be dealing with any interview. As such, there cannot be any legitimate reason for performing research among the critically ill. However, what is telling is exactly this account of the critically ill, they have no voice, they are spatially and temporally static, they are vulnerable and they

⁴ With the exception of the recently deceased, whereby quiet is ensured whilst bereaved family members are present or believed to be present.

accomplish nothing socially. The prevailing attitude toward the critically ill as non-social vulnerable beings does not necessarily follow what is being demonstrated within this ethnography and is in part the reason why such research within the intensive care unit is so important. This issue will be raised again in the following chapter, suffice to say issues concerning giving and allowing voice are extremely important within this chapter.

Chapter Six had as its focus the unconscious body within intensive care, providing a thick description of the materials and spaces that are implicated in the transformation of the sick body into the critically ill body (Place, 2000). How bodies are read in both their presence and absence were presented, and the means through which these bodies are re-presented and made stable both physically and in relation to the representations of monitoring equipment. These issues of inscribing (Latour, 1987) the body and documenting the representations gave another insight into how the body is viewed through the physical materials and organisational processes which in turn render the body legible in a specific way. This specific way of reading the body transforms the abnormal body into a normalised pathological body that has been adapted to 'plug into' supportive therapy. The body of problematic pathology becomes something that can be made sense of, can be read. The *eu-topia ou-topia* of no place and good place within More's Utopia (More, 1969; Hetherington, 1997), exist within the same bodily space within intensive care. The unconscious body is simultaneously the no-body (*eu-corpus*) and the good body (*ou-corpus*). The unknown unconscious body is transformed into representations through 'adaptors' that link it to the technology. At the same time the body is the site of the good, the ideal, paralysed, sedated and legible body from which supportive therapeutics can take place within the body's allocated space. The body becomes a site of heterotopia, which was alluded to in relation to the unconscious body. This chapter is concerned with a particular anatomical site which has particular ambivalent relations to the social; that of the mouth.

The intention for this chapter is to present the mouth as a critical site in relation to the practices of intensive care and as such is a presentation of the sites of intensive care and of the mouth. Intimately bound up with things oral is speech, the means through which real time communication is made with the social world around us in the here and now. As has been presented, intensive care technologies, particularly intubation,

silence the critically ill. This chapter aims to re-present some aspects of the field work conducted within intensive care in which mundane aspects of social life are conducted around the speechless critically ill. Significantly, the illustrations from the field will emphasise how and in what ways the speechless critically ill are actively engaged in the social world around them. Whereas the previous chapter demonstrated how the unconscious critically ill are involved in the social by extension to cultural artefacts, this chapter aims to demonstrate the significance of the conscious critically ill patient. Through much of social theory primacy is accorded to speech (Goffman, 1959; Giddens, 1991) and its transformation into textual form (e.g. Wetherell *et al.*, 2001), the aim here however is to present some of the social 'work' that the critically ill engage in despite their speechlessness.

Positioning the mouth within intensive care.

The mouth within the nursing and medical literature concerning the intensive care area is constructed as a distinct site of medical problematics. Themes concerning the mouth concern oral hygiene and the prevention of trauma. These are issues that are generally held to equate to the problem of respiratory tract infections, which are a particular consequence of supportive respiratory therapies within intensive care. The notion of oral care is widely discussed within the nursing literature (McNeill, 2000; Wilkin, 2002), particularly in relation to the benefits of a particular method of providing oral care and securing the endotracheal tube (Adam & Osborne, 1997; Barnason *et al.*, 1998). 'Good' oral care has long been associated with good nursing care (e.g. Hainsworth, 1949). The fact that it needs to be done for the benefit of the individual's own good is taken as self-evident, with little recourse to the social and experiential implications of such practices.

The mouth is curiously absent within the nursing literature, aside from as an area of pollution or risk, be that concerning intensive care particularly, or other areas of health care practice in general, aside from the focus on the pathological. Indeed, there are numerous texts that pay particular attention to how to perform oral care, its significance and its physical implications (Redfern, 1991; Mallett & Bailey, 1996; Griffiths & Boyle, 1993). Where the social significance of the mouth is recognised, such as in Woodrow's (2000) intensive care nursing text, any thoroughgoing analysis

is conspicuous by its absence, a reliance being made on the physiological and pathological manifestations of oral, and by implication, respiratory disease within the ICU. Within intensive care medicine journals, perhaps more strongly than nursing journals, the mouth is viewed as a site of risk, a space through which chest infections originate. However, the focus tends to be more about treatment and preventative treatments (such as Selective Decontamination of the Digestive tract), yet the mouth remains a problem. The mouth becomes a site of risk again, but this time in relation to nosocomial pneumonia as opposed to specific oral and mechanical consequences of oral endotracheal intubation.

‘...a healthy body was only possible with a healthy mouth...’

(Nettleton, 1988, p162).

The mouth in other domains of health care, such as dentistry has, as one would expect, received attention from sociologists (Nettleton, 1988) and practitioners alike (Griffiths & Boyle, 1993). Whereas some moves have been made to locate the mouth within a broader social context, this has been achieved largely through a call to the development of public health in general and dentistry in particular (Nettleton, 1988). In Nettleton’s case this is presented in relation to a Foucauldian reading of disciplining the body through the mouth. Indeed, the hazards of noxious smells and associated effluvia have long been associated as the basis of nursing care (Nightingale, 1860). Public Health pioneers such as Chadwick helped bring the notion into the domain of public and professional consciousness (Fee & Porter, 1992) implicating the mouth:

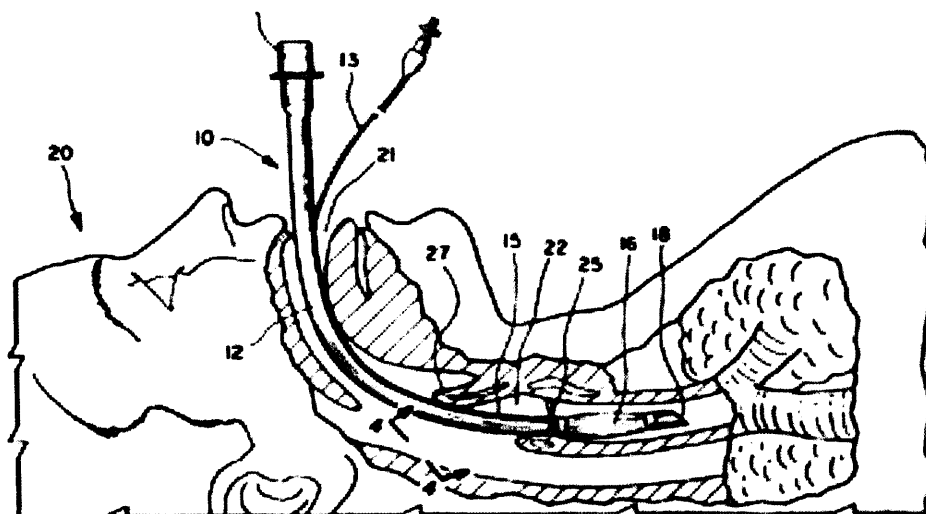
‘...as the boundary between the internal body and the external sources of pollution...’

(Nettleton, 1988, p163).

The faecal-oral route of infection is one of the more common routes of infection and is a core component of contemporary teachings on ‘infection control’ among health care professionals (Meers et al, 1995), being a vivid reminder of the importance of handwashing. Akin to things in the wrong places being polluting (Douglas, 2002), it is through this translocation of microbiological organisms that many aspects of infection control are based and as noted a common example being through the mouth. The mouth is also an area examined by physicians to locate clinical signs of systemic pathology (Hayes & Bell, 1996). It is through the mouth that more general, usually

gastrointestinal, pathology is made visible; that is, the sign seen through the mouth signifies systemic pathology.

The mouth comes under the clinical gaze of medical, dental and public health practitioners. Specifically the mouth is transformed into a site of risk and pollution, and gaining entry to the mouth has as Nettleton has shown (1988) particular disciplining effects (Foucault, 1977; 1998). However, there are particular problems associated with the mouth in the ICU, aside from that witnessed in generalist clinical practice. The mouth has social and personal implications that are largely absent within the professional literature. Within intensive care literature the mouth is rarely referred to aside from risk and pollution, the odd article within the nursing literature may refer in passing to oral discomfort (e.g. Grap et al., 2002) due to the presence of an endotracheal tube, but rarely in relation to meanings this holds for patients and staff. It is both ubiquitous in relation to pathology, yet absent in relation to experiences of the mouth, the significance of the mouth to intensive care is what I hope to demonstrate here and outline some of the areas whereby the mouth gains significance within intensive care.



Picture 7.1 Position of endotracheal tube

The intensive care patient often has a tube inserted into the mouth, in order to facilitate mechanical ventilation and maintain a clear airway (intubation). This not only deprives the patient of speech and the capacity to swallow, cough, clear their throats or even to smell, it also opens the mouth up as a passage to be maintained by

others. Intensive care staff monitor and maintain this passage by entering the mouth with swabs, toothbrushes and suctioning equipment. This has clear clinical significance, yet holds profound consequences to individual bodily experience. The mouth is not only of significance in relation to communication, but as a source of pollution. The endotracheal tube becomes a route to the lungs and as such requires protection against removal in which case the lungs are no longer being ventilated. The mouth needs to be kept clean in order to prevent the slippage of oral and nasal fluids travelling down to the lungs (Cassiere & Niederman, 1997; Langer et al., 1987). The illustration (Picture 7.1) shows the position of the endotracheal tube within the oropharynx. Toward the end of the tube, slightly proximal to the bifurcation of the bronchi (number 18 in Picture 7.1) a balloon (numbered 16) is situated, which is inflated to create a complete circuit between the ventilator and the lungs. Commonly doctors, and more frequently nurses within intensive care, make the comment to patients whilst suctioning the 'goo' that it is just like 'being at the dentist'. As dental visits usually require an examination and infiltration of the oral cavity, the abnormal endotracheal tube is partly normalised. Intensive care is made more normal through reference to the every day outside world, whilst those foreign invasive procedures are made more normal through recourse to the non-intensive care world. The breaching of bodily boundaries through sucking 'goo' from the mouth, the de-polluting practices are part of the every day world of intensive care and intensive care staff are fully aware of the discomforts and frustrations associated with the tubes' presence (as will be seen later).

The mouth within the intensive care unit holds a privileged yet ambiguous position. As will be demonstrated through this chapter, some of the tensions associated with speech and silence within everyday (outside ICU life) are magnified within intensive care. The mouth forms a particular social space, which through functioning in a completely different way to everyday social life provides a fresh insight into the cultural and anatomical space. Whilst the previous chapter emphasised the ideas of legibility and the ascription of identity to unconscious persons *in absentia* through extension to a multiplicity of sources, it made little recourse to ideas surrounding the mouth, even though silencing was seen as a significant process as a means of 'sorting out' the body. It will become increasingly clear that the anatomical space of the

mouth is rendered particularly problematic through the very nature of intensive care technologies.

‘...the danger which is risked by boundary transgression is power. Those vulnerable margins and those attacking forces which threaten to destroy good order represent the power inherent in the cosmos. Ritual which can harness these for the good is harnessing power indeed....’
(Douglas, 2002, p199)

However, there is far more to the mouth than simply a space from which speech emanates. Culturally, the mouth holds a specific position in relation to those specific acts associated with it, kissing, eating, vomiting to name but a few. Within intensive care, the mouth becomes a particular location of vigilance. In Douglas’s terms, it is a vulnerable margin associated with what is on the one hand sacred, whilst on the other hand polluting. Having presented accounts of the civilised and civilising functions of the mouth in the opening sections of this chapter, some insights into the polluting and dangerous aspects of the mouth will be presented. Within this space, betwixt and between (Turner, 1970) everyday cultural representations of the mouth, a fresh insight into the cultural significance of the mouth will be presented. This insight which has broader implications will be illustrated in relation to the field and as such what follows is an illustration of cultural processes associated with the mouth within intensive care. This follows two presentations of field notes, one as a continuous narrative tale and the second broken up with interview materials.

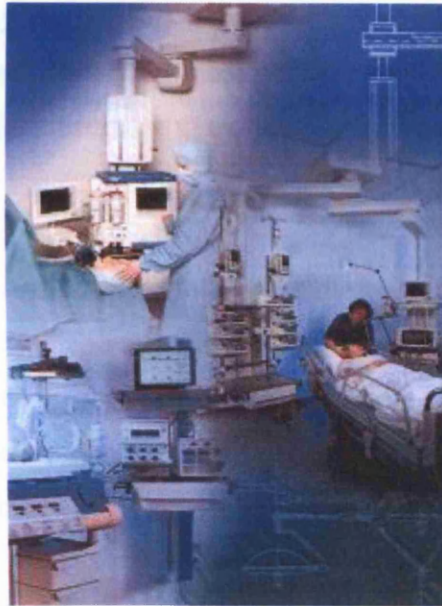
Two ‘funny old men’.

The following account, taken from the fieldwork involves two retired men, admitted to intensive care for quite different reasons and having different lengths of stay. Albert (in Bed 9 in Appendix Four) is in his late 60s, a retired civil servant married to Beryl. Beryl catches the bus at the same time each day arriving in the ICU at about midday, leaving at around half past five, unless she has her shopping to take care of, in which case she generally leaves at about half past two. If she does leave early, she generally asks the nurses whether it would be okay for her to go, whether Albert would mind and only then does she go. After greeting him and giving any pressing news, she retires to the relatives’ room in the main corridor and has a bit of lunch returning to his bedside where she knits or chats to him about their family, the bills, friends who have asked after him, neighbours, their children, pretty much everything

she can think of and everyone she has had contact with outside of the ICU. Albert sometimes took the opportunity to sleep, or at least close his eyes through much of this. Their two children have grown up and have families of their own, both of which have moved far away from the area and visit infrequently. They have a number of friends, former colleagues and neighbours who visit in the evening.

Albert was in intensive care for about ten weeks, admitted with an ascending weakness that was quickly diagnosed as Guillain-Barré syndrome. The disease progress is such that the muscle weakness begins at the feet and ascends the body, which in the more extreme cases continues up the body resulting in paralysis that requires ventilatory support, as in Albert's case. It generally descends after a period of time, with no direct long term consequences aside from that of the supportive technologies themselves and the prolonged period of muscle wastage from lack of use. Albert had become a long-term patient within intensive care, the ward round often involved the consultants talking to him, although he found any reply difficult. He was intubated soon after admission and had a tracheostomy performed within intensive care on the sixth day of his admission, from the outset he was seen as a long-term patient. For the most part, Albert was conscious throughout his admission to intensive care. Whilst dependent upon life sustaining technologies, this was on account of his neurological pathology, aside from which he was normally quite fit and well. It is the tenth day of his admission that is the focus of this section. In particular it is the day that Roy was admitted into the two-bedded space within the unit (bed 8, see Appendix Four) next to Albert and focuses largely on the day that Roy was discharged. But perhaps this space needs clarification.

This particular space within the ICU is quite cramped, it is a space on the 'A side' of the building that is next to the fire doors connecting it to the 'B' side making it pretty much the central space of intensive care. Formerly a paediatric intensive care unit which moved to the opposite 'B' side of intensive care, it was gutted and refashioned as a brand new intensive care unit with a pendant system from which the ventilator could be housed on one side and syringe drivers and pumps on the other (as seen on



Picture 7.2: Pendant System in Bed Area.

the right hand side in the above picture). Whilst the 'B' side of intensive care would be to the left of Albert (or looking at the nurse in the picture, to the right of the bed), Roy's bed is situated to the right of Albert with its own pendant system. To the left of Roy is the Sister's office, then store cupboard, sluice room, pharmacy room, linen room and waste area up to the entrance doors to the 'A side' of ICU. Opposite the beds were two other beds, complete with pendant systems and a large open area separating the two beds from the beds opposite. A controlled drug (CD) cupboard with kitchen unit below which housed patella hammers, Doppler probes, otoscopes, ophthalmoscopes and associated paraphernalia was situated next to the linking doors and a sink was located opposite that. As such it was a thoroughfare which was quite noisy, the doors had the familiar 'critical care patients need rest' signs emblazoned on it, which did not prevent the doors from opening and closing (and thereby making noise). This 'A' side of the unit has nine open plan intensive care beds, however, the location of the supporting concrete pillars and the necessary separation from the 'B' side of the unit for fire regulations makes it feel slightly cut off from the rest of the 'A' side. The two pairs of beds facing each other face on to a thoroughfare through intensive care. In this thoroughfare, nurses check the controlled drugs at night and will call each other to check drugs (the controlled drug laws necessitate two qualified nurses to check any controlled drug out and it is documented and signed for in a ledger) at the CD cupboard throughout the day and night. The sink sees regular use, serving four bed spaces and having four nurses within the area not including the

medical, technical therapy and support staff who wander from bed space to bed space (thereby seeing regular use). This meant that not only was there a whooshing from the sink, but bin lids snapped shut regularly irrespective of time of day or night. But back to Roy.

Roy was admitted post-operatively following the repair of an ascending aortic aneurysm (Triple A repair). Generally these patients would by-pass the intensive care unit, being admitted to the High Dependency Unit from the Recovery Room of the Operating Theatre suite. Here they would be observed overnight for perfusion of their feet and of their blood pressure, they are admitted for 'bed and breakfast' as it is known to intensive care staff, simply for an overnight stay before transfer back to their home ward where their bed should be kept. However, the anaesthetist reported that Roy had a massive drop in blood pressure post-operatively, required an infusion to maintain his blood pressure in addition to additional blood products. He was sedated and ventilated and as such should come to intensive care as he was seen to be too sick to be an appropriate High Dependency admission. He arrived at half past eight in the evening, where the intensive care staff assessed him. From the perspective of the nurse who took handover from the anaesthetist, there was little reason for Roy to be admitted, she felt that it had more to do with having an empty recovery room than it did transferring him straight to the HDU. She felt that if he stayed an hour or so more in recovery, he would be extubated, the inotropic drugs would be off and he could be transferred straight to HDU. The intensive care consultant who later performed the evening ward round echoed this view, the inotropic support was now off but Roy remained sedated and ventilated. The consultant suggested he remain ventilated overnight, 'turn the sedation off now and see what happens, if he wakes up, extubate him'. Roy was extubated the following morning.

It is about eight the following morning and the place is a hive of activity. The day shift of nurses have had handover from the nurse in charge of their allocated area from the night shift, they have a second handover with the individual nurse who was allocated to their newly allocated patient. Some of the night nurses remain to chat before going home, others are still handing over, whilst the majority have gone home. The night shift of junior doctors are discussing the patients with the consultant outside the sister's office, who is making sure that everything is up to date before handover at

ten. The day shift of nurses are listening to the bed-side handover, checking equipment in their bed space or totalling up the past 24 hours of fluid observations. The receptionist is going from bed space to bed space making sure that her chart detailing admissions and discharges is up to date, whilst the care assistants are clattering about with wash trolleys by the sluice room. This is a busy time of day, John a male staff nurse has been allocated to look after Roy, he has checked the charts and equipment and readied a face mask for Roy's extubation. Tristan, another male staff nurse who is allocated to Albert, is busy with Albert's observation chart, passing back and forth from the table at the foot of the bed, to the ventilator (which is to the left of Albert's head, to the right of Tristan's position at the foot of the bed) and back to the foot of the bed. Back to the ventilator, then to the table, writing down. Down toward the syringe drivers to the right of Albert's head, back to the chart, down to the syringes, back to the chart, down to the feed pump, back to the chart, he kneels down at the foot of the bed and drains urine from a bag, over to the sink, back to the table. Pacing back and forth, left side of the bed then back to the table, right side of the bed then back to the table, writing, the calculator comes out, more writing, he swaps the charts for a new one placing the new on top of the old. He looks up to the monitor, down to the chart, writing, back to the monitor, Albert is still asleep.

Roy, still with tube in mouth is mouthing something to John, and smiles. He reaches up for the tube, 'now, now, we'll have that out in a minute' calls John, Roy's hand drops back down to the sides of the bed. John goes over to the right hand side of Roy's head and adjusts the arterial line and draws out a sample of blood into a syringe, the arterial trace on the monitor goes flat and the monitor alarms as he does it, he explains to Roy what he is doing. He calls over to Tristan asking him to 'keep an eye' whilst he 'runs the gas' and walks away to the blood gas machine. Tristan finishes up his writing and walks over to Roy, 'good night?' he asks, Roy shrugs his shoulders and points to the tube in his mouth. 'That'll be out in a sec' states Tristan, and explains that John needs a final check on his numbers before the tube comes out. Roy mouths something to Tristan that I can't read, Tristan laughs, 'you'll be up and running around on the ward in no time'. Albert's ventilator alarms, Tristan walks back over to Albert heeding the call of the ventilator alarm. John returns to his bed space from the gas machine with the blood results on a slip of paper. The results sheet looks a bit like a shopping receipt from a supermarket, he tells Roy that he has 'come up on

his numbers' as though the numbers represented a lottery jackpot win. So John started preparing the equipment and the preparation of Roy so that the oral endotracheal tube could be removed, or more simply so Roy could be extubated. Albert on the other hand had now woken up and was watching John and Roy, Roy looks over and gives him the thumbs up, Albert being largely paralysed as a result of the Guillain-Barré could do nothing but watch and smile, raising his arm slightly.

Within the intensive care unit experienced nurses generally extubate patients, particularly those seen to be unproblematic, such as Roy. A doctor trained in anaesthesia, such as intensivist (for the most part, although there is a consultant in intensive care who has no anaesthetic background), senior registrar or advanced trainee (with training in anaesthesia) is required on the floor of the unit. This is a precautionary measure as the consultant will have stated who is appropriate for extubation and the nurse will have taken an arterial blood gas to determine the patients' respiratory status. However, certain complications resulting from the extubation itself, or indeed factors such as the patient not being 'awake' enough or 'ready' to breath on their own may necessitate immediate re-intubation, hence the presence of an anaesthetic trained doctor. In the mean time the nurse will be able to support breathing manually using an 'Ambu-bag' or Waters circuit and a tight fitting mask, other tools such as laryngeal mask airway are available but seldom used. This is rare as in practice, if the nurse has any doubts about the appropriateness for extubation, they will produce an arterial blood gas to legitimate their claim, or emphasise the work the ventilator is doing, or refer to the patients sedation score (which includes agitation as well as stupor and is discussed in Chapter Eight). If this material evidence for not extubating is ignored, they will either refuse to extubate outright, invoking issues of risk stating that they are unable to re-intubate or demand that the consultant be present at the foot of the bed (a useful device for ensuring that the consultant has thought carefully about extubation).

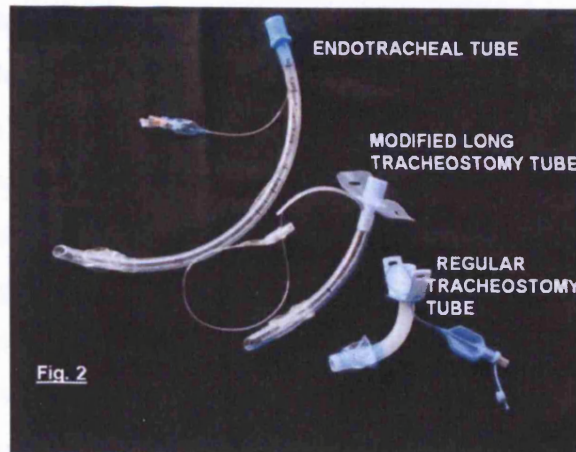


Picture 7.3: Yankeur Suction.

The curtains have been drawn around Albert's bed space by one of the 'Professional Support Nurses'⁵. The care assistant pushes through the closed curtain with a wash trolley, it has one yellow and one red bag attached to the side, laundry on the shelves inside it, a wash bag and what looks like a washing up bowl full of soapy bubbly water is on top. I migrate back to John's bed area where John is finishing off setting up the equipment for Roy's extubation. He has already turned the ventilator settings down so that the ventilator is compensating for the resistance of the tube, which is the reason why he took the last blood gas sample. The face-mask which is attached to a water bath and the oxygen supply through a long piece of wide corrugated tubing, known as elephant tubing, is placed on top of Roy's pillow above his head. John picks up another long piece of clear plastic tubing and switches on the suction unit, then grabs a suction catheter, ripping off the top of the sterile packaging and attaching it to the tube. He takes a sterile glove from under the ventilator with the other hand having looped the non-sterile areas up in the other hand, opens up the paper sleeve and places his hand in the glove. Holding the suction equipment in the hand without the glove, he brings it toward the tube in Roy's mouth. He tells Roy this will be the last time he will be suctioned, opens up a rubber cap on the end of the tube in his mouth, removes the sterile sheath quickly and with his gloved hand pushes the catheter through the end of the tube until about ten or fifteen centimetres remain exposed. Roy coughs, the ventilator alarms and the suction noise grows louder with a sharp gurgling sound as John slowly pulls the tube back out and closes the cap back up. Roy is looking a little red faced, his eyes are watering, John wraps up the catheter in the glove, dips the tube into a bottle of sterile water whilst the tube is still sucking and attaches a rigid angled tube (a Yankeur as illustrated in the above picture) to the end of the suction tube and places it under Roy's pillow. 'Okay Roy, we just need to get that stuff out of your throat a minute' explains John. He passes the Yankeur into Roy's mouth around the endotracheal tube, Roy gags as he does it. John turns to me and asks me to pass him a 10ml syringe from the draw at the foot of the table; I duly pass him the syringe.

The curtains around Albert's bed are still drawn. John tells Roy that when he tells him, he wants him to take a deep breath in and hold it and then breath out when he

⁵ Locally they are known as 'PSNs' or 'floaters' and their role is to support the nurse in charge of a particular area, they will check the arrest trolley, chest drain insertion set, help with turns and washes, teach junior staff, prepare and administer intra-venous drugs for junior staff nurses and 'take an admission' if necessary.



Picture 7.4: Endotracheal and Tracheostomy Tubes.

says so. Roy nods. He attaches the syringe to the cuff (the cuff is the blue bit in the picture above which looks like it is on a bit of string that inflates a balloon at the other end of the tube) and removes the Velcro fastenings securing Roy's endotracheal tube, holding it in position in his fingers. He deflates the balloon which makes Roy cough and pulls the tube straight out. The ventilator alarms, John places the oxygen mask over Roy's face and puts the ventilator into standby mode. Roy is sat up in bed, silent, John throws away the endotracheal tube and places a black rubber breathing bag over the ventilator tube. 'Now you can speak again you've gone all silent on me' jokes John, 'you got nothing to say'. 'Thank God for that' replies Roy. John continues clearing away the equipment as Roy continues to chat. John mutters something to Roy about the fact that he hasn't stopped talking, the curtains get pulled back on Albert's bed space. Albert is now sitting upright in his bed, Roy leans over the side of the 'cot-side' (bars which run along the side of the bed), introducing himself to Albert.

Roy continues to chat with Albert. John has started preparing the paperwork for Roy's transfer out of intensive care (he needs to be transferred out at lunchtime), so is not paying too much attention to Roy. Tristan on the other hand is acting as a mediator in the discussion between the pair of them, reading the lips of Albert and relaying it back to Roy. 'You a city fan Albert?' enquires Roy, referring to the city football team, Albert shrugs, John says he is from a town between two rival football clubs and isn't a football fan. Roy tells Albert that he has been watching the games since he was a boy, John chips in 'you know that you're a City fan if your family tree goes in a straight line', Albert smiles as Roy tells John that he hasn't heard that one before. The football jokes trail off and Roy introduces doctor and nurse jokes, Roy may not be the most

accomplished joke teller, but he spends a lot of the morning laughing. He adds a doctor, doctor joke to his repertoire; doctor, doctor I keep losing my memory, when did you lose it, I don't remember. Albert laughs, his ventilator alarms, so Tristan goes over to it. Albert mouths something to Tristan that he doesn't understand. Tristan asks a battery of questions, 'are you in pain, are you uncomfortable, do you want to change your position', trying to guess at what Albert is saying, Albert mouths 'forget it' and closes his eyes. The banter between Tristan, Roy and John continues through the morning. Roy has a wash and is waiting for a bed to be made available. Albert's eyes remain closed through most of the rest of the morning as the boys joke and get mobilised into the routine work of the day in intensive care.

Albert has just been turned onto his right side, facing Roy who is eating some lunch. Beryl arrives on her daily visit to Albert and goes straight over to Albert. He mouths something to her and she walks over to Tristan and me at the foot of the bed, looking puzzled. She says she thinks he may be a bit confused today and asks if he had a good night sleep. Tristan says that the night staff never mentioned anything, so he didn't have a particularly bad night. I call over to him and ask if he slept okay, he nods. She goes on to say that he said 'he got the joke wrong' or something, Albert mouths her to come over 'it's not I don't remember, it's when did I lose what'. I look over to Albert who is smiling, 'he got the punch line wrong' I ask, Albert nods and Tristan tells Roy how the joke is supposed to be told. The joke is retold with the proper punch line, that makes more sense adds John. Beryl goes off to have her lunch as Roy is prepared for his transfer down to the High Dependency Unit. The Care Assistants prepare the bed for moving as John places wash equipment, notes and X Rays on to the bed, Roy calls out to Albert wishing him good luck and waves as he is rolled out of intensive care. One of the Care Assistants returns with a trolley and a 'washing up bowl' wrapped up in paper, he punches through the paper and takes the bowl to the sink, squirting in some soap. The bed space, missing its bed, is washed down getting ready for the next admission into the space next to Albert, whenever that might be.

So what about 'two funny old men'?

In writing up this aspect of the field notes which details quite prolonged exposure with the four men (five including myself) a more detailed picture of what intensive

care is about on a more mundane day to day level comes to the fore. Whilst this presentation adds to an on going thick description which develops throughout the empirical chapters, the aim here is slightly different. What is significant is the presentation of the significance of the mouth and the stuff of the social world concerned with orality. Not just what speech and speechlessness accomplish (although this is of great significance), but how this makes visible some of the tacit assumptions of intensive care staff toward speech and by implication, the mouth. This comes from looking on at a few hours in the lives of four quite different men and in particular the two elder gentlemen who were in-patients within a particular space within intensive care.

Before and shortly after Roy's admission we see that the mouth has become significant in gaining admission to intensive care in the first instance. Although this was legitimated in relation to poor cardiac output (requiring inotropic support), sedation and mechanical ventilation, it could be argued that something slightly different is in play. The crux of the issue is that Roy was admitted on account of his endotracheal intubation, his mouth and given the contingencies of having an endotracheal tube in position, his lungs have been breached (this was also highlighted in Chapter Six). The normal order of whole bodies, autonomous bodies, un-tethered bodies have been disrupted. In itself this requires a different view of the body. On the one hand if a body is tethered to a mechanical ventilator, the correct space for this tethered body to be 'disposed of' is an intensive care unit. This notion of disposal has been presented in Chapter Two and will be revisited within the discussion, Chapter Nine.

For the intensive care staff, keeping such a tube in post-operatively is viewed as a strategy to secure admission for a patient that may or may not require it. As this reason for admission comes from a position of safety and risk on the part of the anaesthetist, it remains incontestable so for the intensive care staff is not open to discussion. What is open to discussion is the perceived reluctance for the anaesthetist to extubate at a suspicious hour of the evening, close to the end of the shift of Operating Theatre staff. The anaesthetist has the skills to extubate the patient safely, intubation and extubation and the breaching of the mouth is the major part of the role of the anaesthetist. The fact that Roy is admitted at eight o'clock at night and

intensive care practice requires four hours post-extubation prior to ward transfer (not HDU transfer, which would be up to an hour) suggests to the nurse and to some degree the consultant that this strategy has been used. The mouth becomes a space of political contestation between the staff of the ICU and the staff of the recovery room. It is mobilised in a way that is incontestable, yet the perceived motivations remain contested. It is recognised that the lungs through ventilation could similarly be the point of contestation between anaesthetic and intensive care staff owing to the practicalities of breaching the mouth to facilitate ventilation of the lungs, as with the example of the man admitted from the emergency unit (in Chapter Six). Not unlike the previous chapter which aimed to develop understandings of how identity work is performed *in absentia*, the identity of Roy is partially figured through recourse to the anaesthetic staff in relation to his 'reason for admission', which officially is post vascular surgery (a Triple A repair), but unofficially, the anaesthetic staff who 'disposed' of Roy for an 'easy night'. However for now, it will be demonstrated that there is something particularly significant about the mouth within intensive care over and above the lungs, in spite of the lungs being a major feature of intensive care through the provision of mechanical ventilation and specialised forms of respiratory support.

Whilst Roy is read in terms of the actions or inactions of anaesthetic staff, at least for a time, Albert is viewed as a *bona fide* intensive care admission, even though when originally admitted he was relatively (within intensive care terms) fit and healthy. He arrived into the Emergency Unit by ambulance following a home visit by the General Practitioner, where he was reviewed by an Intensivist and Neurologist and deemed an appropriate admission to intensive care. With such a disease (which is seen as self-limiting), the aim is to support the failing neuromuscular system until the disease process runs its course. There are parallels here with the dominant conceptualisation of the development of intensive care, the polio epidemic in Copenhagen (as discussed in Chapter Three). To that extent, Albert is not only a *bona fide* intensive care admission, but part of the very reason for the existence of such units around the world in the first place. In which case he is read as a true intensive care patient, not as an individual but through the pathology he is in his rightful and legitimate space. On arrival within intensive care, he was able to breathe on his own, move his arms and legs (though he could not bear his own weight), but after transfer onto the bed and the

sorting out was well under way, he was intubated. He was informed why he was going to be intubated, that he would need a tracheostomy tube fairly soon and informed of the disease trajectory, he became embedded under quite different circumstances than many admissions. The following chapter will tease out some instances where the admission process may not be seen as quite so civilised, but for now, the work of silencing had been done.

Multiple views of the body have been highlighted in relation to the unconscious body (Chapter Seven). The spaces which Albert and Roy inhabit, enable the performance of certain actions, bin lids crashing, doors closing, water running, people talking and so forth. A recursive logic in which these things happen, are in part a necessary thing to happen, they continue to occur and are legitimated through their continued performance. The sign on the door reminding people to be quiet through recourse to the needs of the critically ill remains incongruous within an environment that is adapted for intensive care staff to treat the critically ill. Conversely, the space is designed for the critically ill to inhabit which makes visible the body and therefore renders the body amenable to treatment. Noise producing actions are tied in with the space of intensive care. The bins and sinks are located close to bed areas as intensive care nurses cannot leave the bed space without another nurse or doctor present, specifically an intensive care nurse or doctor, not an ICU Technician, ICU Physiotherapist or ICU Care Assistant, although there is an increasing argument for the latter to 'take patients' under the supervision of an intensive care nurse. So the location of these 'noisy' items, the bin and the sink are necessary for 'good practice'. Not just that concerning the immediate safety of the patient, but in relation to 'infection control' whereby any staff member who touches the body of the critically ill has to wash their hands after contact with the body. Any staff members who comes into contact with the body has to adhere to what are termed 'universal precautions', which necessitates the wearing of gloves and apron whilst in contact with the patients body (white coats having long since been banned).

With the hourly documentation of observations, the regular administration of drugs, four hourly repositioning of the body of the critically ill, not to mention the routine washes and washes as a result of defaecation, the sinks and bins are in almost constant use. So the position of the sink (one sink covers four bed spaces) and the bin (five

bins cover four bed spaces) are convenient for staff, the sinks do not have normal taps in this space, but have a knee operated tap which produces a timed spray of water to prevent cross-contamination by hand. Intensive care staff have no control over the duration or power of the spray yet must regularly wash their hands and dry their hands. Drying hands on soft white paper towels similarly reduces the risk of infection and need to be disposed of along with dirty gloves and aprons in the bin. There is a specific requirement for the bins to have lids within a clinical environment, so each time it is used it makes noise as it slams shut. The sign that informs anybody who looks at the door that 'Critical Care Patients Need Rest' is incongruent within the context of providing safe care. The sign does not prevent its use, or its necessity.

The sign demanding quiet can be seen as a supplement (Derrida, 1967), a sign that (through the very existence of this particular sign) is a recognition that quiet and rest is missing from practice and the lives of the critically ill. The sign's existence suggests an aid to a discourse of an ideal way in which bodies, or more appropriately patients should be treated. Yet it is of itself a recognition that the bodies of the critically ill are not treated in the same manner as a sick patient. Through a 'bolting on' or 'quick fix' of a sign to an organisational and cultural problem, the sign⁶ is transformed into a meaningless door decoration as the issue underpinning the problem is not addressed. Indeed the cultural space of intensive care demands a visible body, as emphasised in the previous chapter (Chapter Seven), what will become increasingly apparent is that the body also needs to be silent. It remains a ghost of a deeper cultural issue which, it will be argued, has a deeper resonance with speechlessness and the performativity of things social. As a consequence of speechlessness and the difficulty in engaging with the world beyond the bed-space, the immediacy of their concerns cannot be voiced and subsequently cannot be addressed. The routine practices and reasons for being within intensive care can become the very reasons why the 'voice' of the critically ill can be dismissed. It could be argued that through the power of speechlessness (which in turn highlights the power of speech), lies the reasoning for the subjugation of the voiceless. Whilst this is important and has been well documented elsewhere (e.g. Friere, 1990; Habermas, 1992) it does not account for how patients are often engaged with.

⁶ The issue of the sign on the door being a cultural artefact of deeper organisational and by implication cultural issues, will be made more clear later; it has been briefly introduced within Chapter One.

Albert and Roy are actively involved in the world around them, contrary to visions of intensive care being a harbinger of social death (Zussman, 1994; Rier, 2000). Whilst both men were intubated, they were able to communicate (largely through the mediation of the nurses) even if that communication is the mundane stuff of ‘chewing the fat’ with neighbours. Of course the example of Roy and Albert is by no means a ubiquitous event within intensive care, but then it is not a particularly rare one either. Through Roy and the nurses, Albert was engaging with the world around him. The attempt from Albert to wave back at Roy, the engaging with humour, about having a laugh is in part about doing the mundane work of ‘doing being’ social (Sacks, 1984) of being an individual (Rapport, 1997). In a Merleau-Pontyan sense, it demonstrates the embodied nature of being, of engaging in real time communications with others (Merleau-Ponty, 1989) and it is ‘the social’ that is being accomplished even though Albert is betrayed by his body through the effects of the pathology. Even as an ethnographer it is hard not to be bound up with the old men and the young men and the every day banter that is happening even despite the speechlessness of Albert. An active involvement, in the lives of these four people was entered into, for a brief period. An involvement that was difficult to escape from and one that possibly shouldn’t be escaped from, but nevertheless changed the way they were perceived at the time and the way they have been written (and represented). The normal and mundane social was occurring, and as a social being it is hard to escape from, indeed, to be a text book fly on the wall would be to miss the point, that the social is wherever one looks and perhaps more importantly, interacts. But this raises more questions about what Albert was up to, as he was now the only one who could neither speak nor move, but mouthed his way around (as made explicit in Chapters Two and Four).

Albert has been given a taste of a world in which the mouth is breached and entered, albeit for a limited period of time. The normally private space of the mouth becomes a public space, or at least public space to intensive care staff, whereby the intensive care demand access to this area. Issues of resistance to these demands will be examined later in the following chapter (Chapter Eight). John inserts the rigid Yankeur suction (as illustrated in Picture 7.3.) into Roy’s mouth and afterwards passes a suction catheter through the mouth into his lungs. The Yankeur sweeps away debris at the back of Roy’s throat and is sufficiently far back to make him ‘gag’, this in turn is sufficiently far back to ensure that the site of the build of debris is sucked

out. The mouth is cast as both polluted and polluting which ascribes a certain legitimacy to the action of breaching and entering the private. As has been previously noted, preparation for extubation requires the removal of oral fluid as its presence runs the risk of infiltrating the lungs (Mehta, 1972), leading to a chest infection. Whilst John is preparing Roy for extubation, the focus again is upon the mouth. Oral 'goo' needs to be sucked away from the mouth, the pollution needs to be exorcised, so that Roy can infect the surrounding area with his humour.

For Albert on the other hand, the necessity of mechanical ventilation rendered him speechless, the vagaries of his neuromuscular pathology rendered him immobile. Even so on a rudimentary level, he was able to communicate with others such as Roy and the nurses through nodding and shaking of his head, and mouthing of words. The difficulty remained with the initiation of communication and more complex responses, such as engaging with a joke. The lack of speech in particular took away the real time nature of communication as the correct or alternate punch-line was not brought up until hours later, something Robillard (1999) was at pains to demonstrate. For their part the nurses engaged with Albert, actively promoting the doing of social. However, the physical proximity of two person's, nurse and patient, who rarely spend more than a metre apart for twelve hours at a time, could arguably become strained. Having to look at a persons mouth and having your mouth stared at for prolonged periods of time is not something that is ordinarily equated with normal social life. Ironically then, disengaging with the social such as through Albert closing his eyes, in many respects then becomes the way of doing social of still having some control over his life which is so firmly controlled by the constant presence of intensive care staff and the absolute control of his body through supportive technologies, particularly the ventilator.

So from this brief outline of a few hours of fieldwork and the writing of that ethnography a number of issues have been raised surrounding the mouth and orality within intensive care and to a small degree, health care in general. Some issues arose as a result of writing this ethnography, which have not been discussed. This includes the intensive care nurses' negotiation of space, although this was touched on in relation to proximity to patients, or more specifically Albert, and the way Beryl, his wife, is moved in certain ways by the environment. The meanings associated with

monitoring, both symbolic meanings such as a flattened arterial trace and the meanings this has for intensive care staff, such as 'running a gas'. This is because it had less to do with the mouth and orality and will be briefly broached in the following chapter (Chapter Eight). On the other hand they have been included as they enabled the continuity of the narrative; they were part and parcel of the fieldwork and were temporally located within the sequence of a few hours. Hence, the inclusion of these indirectly related but not discussed aspects of the lives of Roy, Albert and the intensive care nurses was simply for reasons of flow and completeness. The overriding aim was to create a description of the mundane and the every day, using a particular ethnographic moment to highlight the mouth and orality within intensive care.

In not being able to tell, or correct the joke, Albert tried to communicate to Roy and the nurses. He was actively involved in the convivial atmosphere of this space at this time. As Merleau-Ponty (1989) makes clear it is through this engagement with others that the embodied being is exposed. To some degree Tristan can be seen as effacing embodiment. It is one of the moments in which the body as object takes pre-eminence over the embodied accomplishments of the subject (Rapport, 2003). It can be re-read as are you in physical pain (that he can treat), are you uncomfortable (he can reposition the physical body), do you need suction (he can remove sputum from the lungs). Whilst on the one hand engaging with Albert as a subject, he is limiting this concern for the body as a 'broken' physical object. Albert, through the powerful discursive gaze of intensive care has been partially objectified. His wife asks permission before she leaves and knows that the times she visits are convenient for both her and more importantly the staff; normal (outside intensive care) relations are rendered temporally static. The old rules do not work any more, the immediate reflexive nature of interaction is incompatible within the discourse of being an intensive care patient, the technologies of silence and dependence within a culture of control help to ensure that. But then, is Albert effaced to the extent that he is unable to accomplish being social? Perhaps not (Rapport, 2003).

Engagement with patients by intensive care nurses can be relentless, as has been seen with the proximity of the nurse and the routine nature of their practice. The pressures of working and legitimating practice according to tasks performed around patients

enables the nurse to view patients, such as Albert in relation to solvable concerns, a problem to 'sort out'. As a silent body (Murphy, 2001), engagement with everyday interaction is not necessarily expected, desired or invited. For Tristan there are infinite possibilities for what it is that Albert could be communicating or attempting to communicate, so for him the easiest option would be to run through the most likely options, developed from experience within intensive care⁷. Tristan on the other hand had introduced the most likely things that an intensive care patient would want or need based on his experiences of dealing with many intensive care patients before. However, once the possibilities of communication fall outside of the known pattern of experiences that are treatable, then the possibilities become infinite and Tristan can no longer effectively attend to Albert. Within the climate of the embodied subject and the 'broken' bodily object, there is little recourse for Albert. Whilst not being able to engage in the social, he retains the ability and right to disengage, to close his eyes and metaphorically at least, close the world out from around him. Albert retains his ability to efface the social, to not be 'doing being social' (Sacks, 1984).

So the aim of this chapter is to present some issues surrounding the mouth as they occur within intensive care. At times the text has strayed out of focus in order to maintain narrative flow. It could be argued that allowing the flow of narrative prevents centring on the subject matter, to decentre the writing of ethnography, which in part allows issues concerning the mouth to be seen from a particular standpoint, in this instance of an ethnographer looking on and engaging with the social world of intensive care. At times the mouth has been referred to in passing, but it emerges, tacitly and at times explicitly as a site of ambiguity between speech and speechlessness on the one hand and the site of risk and contamination on the other, an issue which will be made more explicit in the following chapter. The inability to articulate frustrations, the discomforts (particularly for Roy who had an endotracheal tube in-situ and was desperate for its removal), the breaching of a private space are stark reminders of the significance of the mouth within ordinary social life. Perhaps more surprising is the seeming acceptance of these actions upon it. Within the context of a controlling environment this doesn't necessarily seem surprising, as numerous

⁷ This is not too unlike the use of communication boards that Bauby (1997) used to communicate with while physically paralysed (with the exception of one eyelid). The board had the most frequently used letters in the language; he would blink when the appropriate letter was mentioned and slowly build up words.

controlling technologies are around and the intensive care staff are all seeing, but this will be highlighted in the following chapter.

Having laid some ground work on the constitution of spaces, the embodied spaces that invoke a certain reaction or emotion, reminiscent of Bachelard (1994), to the correct spaces, the proper spaces that an intensive care patient should inhabit as well as those in the wrong spaces, reminiscent of Turner (1970) and Douglas (2002). So far a rudimentary attempt has been made to highlight the multiplicity of spaces in which the social is being accomplished in numerous ways. The theme of the mouth as a distinct physical and metaphorical space will be introduced in the following chapter. The intention here is to provide a platform from which further analysis of spaces and those spaces between spaces, the multiplicity of spatiality as it occurs within intensive care whilst reintroducing the body to those multitudinous spaces can and do occur. In short, a brief sketch of the mouth as a distinct space has been put forward, but there are far more issues involved than this chapter can cope with. So instead of two different men, the following chapter focuses on some women in intensive care not for any issues surrounding gender, more because their experiences were quite different to Albert's and Roy's, they just happened to be a few older women within intensive care.

Chapter Eight.

On Breaching Orality: some tales of some women.

Introduction.

The aim of this chapter is to continue from the position of the mouth within intensive care as set up through the previous chapter. The previous chapter highlighted issues surrounding the tethering of the body through the mouth. That is the means through which the body is linked and breached by an endotracheal tube to a means of mechanical or manual ventilation. It peered into the lives of Albert and Roy, two intensive care patients with quite different experiences of critical illness and intensive care. Through viewing them, and those at work around them, some issues concerning the polluting aspects of the mouth, issues of silence and silencing were made visible. Beyond intensive care, this provides some clues toward the significance of speech within interaction within everyday social life. In turn this brought to the fore issues about how the performance of the social continued regardless; that is how the individual transcended technologies of silence (Rapport, 1997). Developing issues of pollution, risk and furthering analysis of speechlessness, this chapter aims to draw out and elaborate on the mouth through recourse to other intensive care patients and intensive care staff.

Even though, common-sensically, the treatment of and inferences made about Albert and Roy may not seem particularly ideal, for intensive care they are archetypal cases of 'doing good intensive care'. Roy on the one hand simply stayed over night for 'more intensive observation and treatment than he would receive on a general ward'. This, as was demonstrated in Chapter Two, is the classic Intensive Care Society (1997) definition of itself which is also the criteria for admission to intensive care in the first place. Whilst there were some issues surrounding the motivation for his admission as perceived by the intensive care staff, in the end this was not seen as sufficient reason for him to not be admitted, aside from this, his mouth had been breached by an endotracheal tube. Chapter Seven highlighted some of the issues of gaining admission and how patients can literally be turned away at the front door; Roy however, gained access. Albert on the other hand was a classic intensive care

admission, traditionally the 'bread and butter' work of intensive care and a potent reason for the development of intensive care, as it is now known, following the 1952 Copenhagen Polio epidemic (as discussed in Chapter Two).

However, Roy and Albert require quite different ways of viewing and treating the body on a practical intensive care level. Both of them are required to wait, either for extubation or for the pathology to reach its descendancy. The differences in waiting times are between hours and minutes for Roy and weeks or months for Albert. Roy waits for his extubation so that he can be back to 'his old self' ready for transfer back to the ward. Albert on the other hand is waiting for his disease to get worse to ascend his body before it can descend; the temporal markers for both of them are radically different. From the standpoint of the intensive care staff, they require a slightly different approach, Roy needs to be encouraged to do things for himself, perform deep breathing exercises, cough to expectorate sputum and is being prepared to be in a position to be 'his old self' again. Albert needs comfort, to not do anything strenuous, to get used to waiting so that at some unspecified point in the future he can be 'his old self', whatever that might be. This chapter focuses on some other patients within intensive care who, from my perspective as an observer, have quite different experiences and have been treated quite differently by intensive care staff. The differences in treatment are for numerous reasons. Through them an insight into the significance of the mouth within intensive care can be made, from which an appreciation of the moral ordering of speechlessness and the social can be made in general and intensive care in particular.

On 'doing being' and being effaced.

Jean is a woman who has been in intensive care for about two weeks (in bed 14, see Appendix Four) following colo-rectal surgery; she had failed extubation (Schwartz, 1997) on a single occasion during her intensive care stay. A failed extubation simply means she was extubated, such as we saw with Roy, but subsequently required re-intubation as she required greater support with her breathing than was envisaged prior to extubation. As a consequence, she had an oral endotracheal tube in position for a longer period than was generally viewed as acceptable. Normally, the endotracheal tube is in place for less than a week as mentioned in the previous chapter. From an

intensive care perspective, the longer an endotracheal tube remains in the mouth, the greater the risk of developing a chest infection as a consequence (Torres *et al.*, 1990) although this is disputed (Rumbak *et al.*, 2004). Perhaps more significantly (as there is a far greater evidence base), it can lead to many different types of laryngeal trauma (Colice *et al.*, 1989; Schwartz, 1997) which have particular long term consequences, such as permanent voice loss, fistula formation between the oesophagus and trachea, and so on. Suffice to say, the consequences of long term endotracheal intubation are not too good. As a result of this failed extubation, the duration of her admission was far longer than was anticipated.

I had been trying for a number of days to enrol her as a participant in the ethnography. I regularly spoke with members of her family about whether she would ordinarily be involved in the study. I explained to them what the ethnography was about and that her perspective as a woman who had been intubated and then failed extubation would provide an important means through which intensive care and some of the effects of its core technologies could be understood. They were unwilling to give their opinion of what they think Jean may want so I made recourse to Jean, the nursing staff and medical staff. Jean agreed to be a part of the study, but then she agreed to most things that anybody within intensive care asked. In intensive care terms, she was a 'compliant patient'; she was pleasant enough for the most part (as we shall see) and cooperated with the intensive care staff. I received her consent to be in the study shortly before she was extubated. However, what the intensive care staff knew of Jean and what I knew of Jean was through her actions and reactions to intensive care. Quite a few people came to see her and they seemed to arrive in groups. However, the ICU has a policy of only two visitors at each bed area at a time, which is legitimated through calls to limitations of space and 'patient privacy', so they took it in turns to visit her.

Jean had developed quite a reputation for herself among the staff. By the time I had met her she had developed her own strategies for attracting the attention of the intensive care staff and this was in part a reason for wanting to enrol her into the ethnography. This consisted of looking at the person that she wanted to attract the attention of whilst hitting the side of the bed with her hand. This would be repeated, growing louder until the staff member that she required came over to her. She had a

reputation as a 'bed slapper' among the intensive care staff. This could be seen as another means through which intensive care patients are known through their actions. Whilst she was never explicitly referred to as a 'bed slapper' as such, if staff needed to differentiate her from another patient, she could be identified through such action. This happened following handover, when nurses are allocated to patients in a private space within the intensive care unit when a nurse needed clarification of who exactly Jean was, 'oh you know her, she's the one who keeps slapping the hell out of the cot sides in bed fourteen'. For patients who are unable to move their arms, such as those with a spinal injury or, like Albert, have Guillain-Barré, they sometimes attract attention by 'clicking' using their teeth and tongue. This is not presented as a taxonomy of how people with quite awful pathology secure attention, more a recognition that where the old methods no longer work in intensive care, new means are found to attract attention. Often these new methods are introduced by nurses themselves and suggested as means of gaining attention. These new means of securing the attention of others seem to work quite efficiently, enabling communication either written or 'mouthed'. Jean however, whether for good or ill, was a 'bed slapper', but sometimes this meant she missed out on something; some everyday aspects of the social were being effaced.

Paul: You seemed to get people's attention easily enough though

Jean: Well, I tapped the side of the bed and the nurses, oh they're ever so good, they come over and read my lips, mostly they get it right and do whatever I need, change my pillows or whatever, but they just turn around and do something else. I know they're very busy, but I feel bad that each time they did something for me, I tried to say thank you, but by that time they had walked away so couldn't see what I was saying.

(From follow-up interview in ICU)

For Jean the nurses, in particular, were so attentive and 'mostly [got] it right', but this attention came at a price. They were able to do the instrumental things for her and read her lips correctly, for the most part, but something was missing. Like Tristan in Chapter Seven, when reading mouthed words, such as an alternate or correct joke punch-line, it was misinterpreted and in the case of Albert, he just left it unsaid until his wife came in. The punch-line becomes a cue for the need of 'nursing care' and not necessarily the mundane stuff of being social. For Albert the cue was being involved in the social but it was being read as an instrumental demand. In Jean's case this doing the normal stuff of being social constituted expressions of gratitude, whilst for Albert it was about being a part of and engaging with a group of people within a given space. In part this can be read as a direct consequence of the proximity Jean shares

with the nurses, as alluded to in Chapter Eight, that with such forced attention there may be a discomfort about continually engaging with another, particularly when it interferes with the rigid routines of intensive care work. What can be seen through these accomplishments are the nurses turning and doing something else, be that charting observations, drawing-up intra-venous drugs, discussions with colleagues or whatever, what is dismissed is the normal conventions of social life. But then intensive care isn't exactly normal, nor are its conventions. But these abnormal situations of speechlessness, immobility and the difficulty in performing the mundane interaction of social life are normalised, made part and parcel of the cultural milieu of intensive care. Having said that, it demonstrates that intensive care patients are active participants in the world around them, being actively involved in the reality of intensive care as they see it. The fact that intensive care does not stick to the normal rules of social convention that would require engagement with Jean, for example, demonstrates in part that something else is happening here and perhaps this is bound up with the mouth and requires a bit more thought.

For Goffman (1959) identity is performed through interaction, through face work with another (1982). The cues and content of talk that are given and received construct an idea of who selves and other are as personhood takes place through interaction. There are more subtle moves made in the everyday social world which prompts a look away or a look toward. For example as I walk along the pavement and witness somebody walking toward me, I do not stare at them; I do not wish to engage with them. I look to the ground, I look up to face them as we get closer and my gaze goes toward the side. I recognise they exist but I do not feel comfortable looking at them, when they have passed I can resume looking ahead normally, looking straight ahead. For Goffman (1963), this can be read as a form of civil inattention and from my experience this is bound up with saving face and not being called to account, to interact; it is to do with the potentiality of being 'caught out' invading another's space through my gaze. I seek another space to rest my eyes, a middle distance, so as not to call attention to myself and not be called attention to by another.

Albert from Chapter Seven is reflexively engaged with performing social as an embodied subject whilst paradoxically located within a body that fails him. For Jean, the more subtle aspects of social life are entered into and effaced. Such effacement

can be read as an effect of speechlessness itself. It is recognised that on one level, Jean could be engaging in a similarly Merleau-Pontyan way as Albert, through the expressions of gratitude. The difference could well be in the way in which the nurses respond, they are elsewhere doing other things, too busy to engage in contact with her, metaphorically they avert their eyes from Jean, look away through calls to some other issue, some other task. On another level it could demonstrate how deeply entrenched the conventions of mundane social life actually are. It would appear to take quite a lot of effort, seemingly more than the medical technologies and technologies of effacement for these engrained performances of social life to be lost. As a 'bed slapper', the ways through which nurses engage with Jean are slightly altered; attention can legitimately be shifted away from her as she will alert the staff when she requires something. However, like Tristan's guesswork at the joke, this demands more time on the part of the nurse than presumably they are willing to give. Jean has in part become her action, she is her means through which she is known and makes herself known to others. From the perspective of the nurses dealing with her, she is the 'bed slapper', and one that the intensive care staff find difficult to extricate from the sustaining medical technologies, both as an embodied subject and an object of medical attention.

The previous chapter looked at some examples of how 'social' is being performed by speechless intensive care patients, such as the mouthing of Roy and Albert. Jean presents another interactional problem, how to get somebody to notice you in the first instance, how to call attention to oneself without recourse to speech. Perhaps the most obvious example is the wave and sometimes this is a strategy employed by the critically ill, but is often discouraged by intensive care nurses. Logically, through the way that nurses negotiate the bed space this would make an ideal means of calling attention, particularly as nurses are focussed for the most part on and around the body. The nurses are engrossed in a certain way of seeing which focuses on the mouth, the body and those tethering accoutrements of technology. The ways in which the technologies themselves transform the gaze of intensive care staff have been discussed in Chapter Six. However, the numbers of lines which tether the body to the technologies of, for example, syringe drivers and monitors make the wave a difficult thing to accomplish. Waving arms runs the risk of admonishment from intensive care staff should a line or cannula come out. This is particularly the case as arterial lines

for monitoring (as discussed in Chapter Six) and venous lines (for non-irritant infusions) are inserted into the upper limbs. Within such a context, Jean's strategy of gaining attention works very efficiently for her, without running the risk of decannulation of arterial and venous lines. On the face of it, this strategy would appear to be one that does not fall foul of discourses of risk, yet the way such actions are discussed by intensive care staff suggests it is an action that they find quite irritating.

When I spoke to Jean after she was extubated, finally, she spoke about the fear of not being able to talk ever again. She could not recall anybody telling her that her voice loss would be temporary until the tube came out. Ordinarily, intensive care staff would not explain that the voice loss would be temporary with somebody who has an endotracheal tube in place; this is a concern that is most often associated with those who have had a tracheostomy performed. This however, did not stop Jean from worrying about the impact this would have on her life, assuming she would leave intensive care. For Jean a permanent loss of speech was something that terrified her, this was perhaps made worse by the fact that she couldn't seek, or at least be understood in seeking clarification over whether or not her voice loss would be permanent. At home, Jean lived with one of her daughters, who has learning disabilities. The intensive care staff were aware of her home life as a carer, that her daughter was staying with another of her daughters and their family and that she had learning disabilities, yet they had no idea of her concerns. Jean's particular fear about her voice loss was that she was her daughter's main carer; she did the talking for both of them.

Paul: I bet you're glad to see the back of that tube

Jean: Yes, I was scared that I would never speak again, my daughter has cerebral palsy and I look after her at home. I do most of the talking for her, it's just me and [my daughter] so I was very worried

(From interview on High Dependency Unit)

Like most people, speech was seen as of prime importance in the life of Jean and one that should not be denied. The ability to speak was of the utmost importance for Jean and by implication for her daughter in the conduct of their lives. Unlike most people, Jean was acutely aware of the significance of speech within ordinary social life through her experience of caring for her daughter. This was an aspect of Jean that none of the intensive care staff were aware of. For the intensive care staff, she was

able to be differentiated from other patients through her technique of attracting the attention of staff. Jean the mother, Jean the carer, Jean the voice of the household, had no place within the order of intensive care, she was the lady in Bed Fourteen, the subtotal colectomy, the failed extubation, the 'bed slapper', in talk among intensive care staff. She became the actions she performed, but she also provides a good insight into the significance of speech within social life in general and an example of how to accomplish 'pillow-changing' within intensive care.

Having taken a brief look at Jean, and one of her concerns in particular, what is being emphasised is the significance of speech in everyday social life. On the face of it, this would appear to be obvious, it is through speech that we negotiate and construct the world around us, but the finer details of how significant it is, in more mundane social encounters is exposed through examples such as that of Jean. For Jean, being able to attract the attention of staff becomes a hurdle that needs to be broached and she develops strategies to achieve this. The significance of speech to her is bound up with her daughter and her role at home as the voice for the pair of them, when this is perceived to be lost 'it just doesn't bear thinking about'. For this part of the chapter Dottie will be re-introduced (from Chapter Four). In common with Jean, Albert and Roy, Dottie, through her speechlessness is able to demonstrate the performance of herself. She does 'being Dottie' despite the controlling effects of intensive care technology.

On silence and the social.

Unlike those patients presented before, Dottie (who was in bed 13, see appendix Four) resisted having an endotracheal tube in place. The situation that Dottie found herself in within intensive care provides an interesting insight into how and what is being accomplished within intensive care, not just from the perspective of the staff or indeed the intensive care technologies, but what Dottie was herself accomplishing whilst remaining speechless. Initially, she was admitted to one of the hospital's general medical wards, experiencing chest pain and some difficulty with her breathing. The ward doctors had ruled out through analysis of her electrocardiogram (ECG) any cardiac problem, so she was due to be discharged home from the ward the following day. Her prescription for the drugs she needed to take home with her had

been written; it was found in the medical notes by the intensive care nurse on admission, which brought forth a few sarcastic comments and a few smiles from both the medical and nursing staff in intensive care. The notes from the ward stated that at around midnight, the ward nurse noticed her looking a little unwell so checked her oxygen saturation levels with a probe. Finding that the levels were too low, she called the junior doctor, who referred her to the intensive care doctors. The consultant intensivist visited her on the ward and agreed that she would need admission to intensive care; in particular she required some form of artificial ventilation and transferred her to the ICU at 02:00. On admission, she was technologised through the insertion of various cannulae into her veins and radial artery (as noted in Chapter Six), the arterial line being seen as essential in the early recognition of breathing difficulties (the arterial blood gas) and prevention of electrolyte imbalance (particularly potassium and magnesium), whilst hooked up to the monitoring equipment which hung from the ceiling just behind the head of the bed, on the 'B' side of intensive care.



Picture 8.1: Non-Invasive Ventilation.

Initially she was ventilated non-invasively through a tight fitting mask (as in the above illustration), but this did not help her breathing. So, as has been mentioned previously, in order to facilitate mechanical ventilation an endotracheal (ET) tube had to be inserted, this was a difficult intubation, explained by the consultant intensivist as being caused by her 'dryness'. That is, due to the lack of lubrication in the oropharynx, the laryngoscope did not pass easily. Dottie was paralysed and sedated for the procedure of intubation, referred to as a rapid sequence induction and was performed by the intensivist enabling Dottie to receive mechanical ventilatory support via her oral endotracheal tube. By 05:00, Dottie had awoken from her anaesthetic and quickly removed the endotracheal tube inserted by the consultant, this is not generally recommended, not just because it appears quite uncomfortable, but due to a serious

risk of permanent speech loss due to trauma of the vocal chords when the tube is removed whilst the balloon remains inflated (as discussed in Chapter Seven). The nurse looking after her had turned around to concentrate on other things around the bed area, and at this point she removed her ET tube, thereby receiving no assistance from the ventilator. The tube was replaced promptly by the intensivist and orders were given to the staff nurse to maintain Dottie's sedation of propofol 'to stop her pulling at the tube', until the ward round in the morning. On account of the awkwardness of performing the intubation, and no small amount due to it being five in the morning, the sedation was seen as appropriate by the intensivist.

The consultant intensivist asked for the infusions to be stopped before the morning ward round at 10:30 so that they could assess 'what she can do' when awake and presumably less agitated. Shortly after the sedative infusions had been switched off, whilst a different intensivist was present, she made another attempt at removing the ET tube. He suggested commencing clonidine (a hypo-tensive agent which is associated with easing benzodiazepine withdrawal) and to continue with the propofol infusion, giving bolus's of the drug when necessary (this could be seen as a euphemism for 'when she moved'). She remained with these drugs for a number of days during the fieldwork until she had a percutaneous dilatational tracheotomy (PDT) performed. However, what we know of Dottie has been raced through in relation to her pathology and the process of her admission at the expense of some issues that having been occurring, so it is important to get back to that.

Sister: This bed area is an absolute tip, whose bed area is this

Staff Nurse: Umm, its Clive's, but he has been busy

Sister: I should have known it was a boy's bed area

((Clive the Senior Staff Nurse returns to the bed area))

Sister: Your bed area is an absolute disgrace

Clive: Well, she's been intubated twice overnight, what do you expect

Sister: look at this ((she points to a used endotracheal tube covered in goo on the worktop beside the bed))

Clive: Well she's still alive isn't she

Sister: I hope you're going to clear up some of your mess before the day shift come in

(From field recording)

To focus too intently upon Dottie is to become so engrossed in Dottie that those aspects of the social that impinge upon her could be lost. Conversely, through looking at Dottie, those other aspects of intensive care life come to the fore, such as the extract above. Within this short encounter between the three nurses, we view whose

risk of permanent speech loss due to trauma of the vocal chords when the tube is removed whilst the balloon remains inflated (as discussed in Chapter Seven). The nurse looking after her had turned around to concentrate on other things around the bed area, and at this point she removed her ET tube, thereby receiving no assistance from the ventilator. The tube was replaced promptly by the intensivist and orders were given to the staff nurse to maintain Dottie's sedation of propofol 'to stop her pulling at the tube', until the ward round in the morning. On account of the awkwardness of performing the intubation, and no small amount due to it being five in the morning, the sedation was seen as appropriate by the intensivist.

The consultant intensivist asked for the infusions to be stopped before the morning ward round at 10:30 so that they could assess 'what she can do' when awake and presumably less agitated. Shortly after the sedative infusions had been switched off, whilst a different intensivist was present, she made another attempt at removing the ET tube. He suggested commencing clonidine (a hypo-tensive agent which is associated with easing benzodiazepine withdrawal) and to continue with the propofol infusion, giving bolus's of the drug when necessary (this could be seen as a euphemism for 'when she moved'). She remained with these drugs for a number of days during the fieldwork until she had a percutaneous dilatational tracheotomy (PDT) performed. However, what we know of Dottie has been raced through in relation to her pathology and the process of her admission at the expense of some issues that having been occurring, so it is important to get back to that.

Sister: This bed area is an absolute tip, whose bed area is this
Staff Nurse: Umm, its Clive's, but he has been busy
Sister: I should have known it was a boy's bed area
((Clive the Senior Staff Nurse returns to the bed area))
Sister: Your bed area is an absolute disgrace
Clive: Well, she's been intubated twice overnight, what do you expect
Sister: look at this ((she points to a used endotracheal tube covered in goo on the worktop beside the bed))
Clive: Well she's still alive isn't she
Sister: I hope you're going to clear up some of your mess before the day shift come in
(From field recording)

To focus too intently upon Dottie is to become so engrossed in Dottie that those aspects of the social that impinge upon her could be lost. Conversely, through looking at Dottie, those other aspects of intensive care life come to the fore, such as the extract above. Within this short encounter between the three nurses, we view whose

space is whose, a sort of ownership of space (as discussed in Chapter Six). From Clive's perspective, he had set up a non-invasive ventilation device and given Dottie a tight fitting mask, whilst the first intubation was planned but quick, the second was an emergency intubation and as a result the debris from the first intubation was still present during the second. For Sister, the mess is a consequence of having male nurses, full stop. As an older experienced nurse, she had developed her own opinions on the place of men and that was not necessarily as a nurse, as they 'need picking up after them'. The staff nurse in the bed next door is already doing some repair work to save face of Clive, providing a reason for the mess, but for Clive getting Dottie sorted out was a far greater priority than ensuring that the 'unit' looked clean and tidy for the following shift. Since Dottie had woken up after the first intubation, she was reaching for the tube which meant that Clive was spending a fair amount of his time walking back to Dottie and removing her hands from the tube. When the tube came out, he was preparing the morning drugs whilst 'keeping an eye' on the patient next door as the staff nurse was taking a break; it is common practice for a nurse to take responsibility for two patients whilst relieving for break. So Dottie, admitted to intensive care for approximately three hours, had removed her endotracheal tube once and as a consequence the following morning ward round found her sedated and intubated, at least for a time.

Having been within intensive care from about five in the morning, I followed the ward round until eleven and went home returning in the evening to perform more fieldwork. Checking with the nurses and the charts it became apparent that Dottie had been sedated with propofol all day. This was hardly surprising as during the ward round when the anaesthetic drugs had been switched off, Dottie again reached for her tube, the junior doctor and nurse preventing her from extubating herself by firmly grabbing hold of her wrists whilst the nurse in charge drew up a sedative drug and administered a bolus. As this was her second extubation, the consultant on for the day decided to follow the precedent set by the overnight consultant and prescribed the infusion to remain on through the day. The cycle continued for another two days, she was sedated, the ward round discussed her case and felt that sedation was inappropriate, the sedation was removed and she self-extubated, so she was re-intubated again.

The following day, day two of Dottie's admission, another consultant has come on and asked 'since when has extubation been an indication for anaesthesia', of course it never has been. Dottie, as far as the intensive care staff are concerned, is simply a difficult patient to manage. The sedation was turned down and again Dottie went for her tube, so by the fourth day of Dottie's admission a tracheostomy is performed. Dottie remained on the sedative infusion with the endotracheal tube until the third day. With yet another consultant on, it was decided that it would be better for her if she had a tracheostomy; his reasoning was that she must be finding the endotracheal tube uncomfortable in her mouth, which is why she keeps removing it. It was decided that the family should be informed that the tracheostomy should be performed on her as it would be more comfortable and enable the staff to wean her from the ventilation more easily. Dottie had been figured as a 'difficult' patient, on account of repeatedly attempting (sometimes successfully) to extubate herself. Within intensive care self-extubation as it is termed, is extremely problematic as it can not only lead to laryngeal trauma such as permanent voice loss, swallowing problems and so on, but because it means a new tube is required and the procedure of intubation is well documented as having its own risks, such as death, which is part of the reason that anaesthetists perform the procedure. As we saw with Jean in the opening section of this chapter, it also delays weaning from the ventilator. So, as far as the intensive care staff are concerned Dottie is a danger to herself, and the strategy on the part of the intensive care consultant was to perform a tracheostomy.

The procedure is performed in Dottie's bed in Neville's (the nurse's) bed-space. As the consultant was preparing for the procedure a nurse asked if 'her' student could watch, asking if he could talk through it whilst he performs it. 'Well you see, we are just going to slit Mrs. Dobson's throat', he and a few of the intensive care staff smile, the student looks a bit taken aback. The consultant is performing in front of an audience, there are two technicians, one who prepared a bronchoscope which he didn't use, the second has a student Operating Department Assistant (ODA) with him, Neville the nurse looking after Dottie, has a student with him as well as the student that was informed of the throat slitting, a registrar who was performing an anaesthetist role, securing the oral endotracheal tube and a Professional Support Nurse, who took the role of second anaesthetist, preparing and administering drugs.

Dottie is led flat in the bed with the head tilted down, she is covered with a sheet, her face, neck and arms exposed, she is paralysed and sedated in order for the procedure to be performed. The consultant is already 'scrubbed' having prepared to perform a bronchoscopy on her (but didn't) and is handed various pieces of equipment by the registrar. The registrar then takes the consultant's position at the head of the bed and holds the endotracheal tube whilst the procedure is being performed on her from the side of the bed. Her neck is 'painted' with a pink liquid (chlorhexidine, an antibacterial agent), and a blue drape with a small hole in the centre, which is placed over her face, exposing the unmarked tracheostomy site. She is now covered apart from her arms, her head remains straight, a bag of fluid is placed behind her shoulders (to hyper-extend her neck, allowing access to the site). Talk is constituted over and around Dottie, her face is covered, no eye contact can be entered into. I have not observed Dottie being involved or informed of what is going on. The focus of attention is on her neck. There is a humorous atmosphere, a number of students and new staff are present to watch. As the tracheotomy is being performed, the observers continued with their business, the consultant, now leaning directly over Dottie's head jokes about not needing the bronchoscope (which is used for difficult intubations), to which the nurse responded that it was more through luck than judgement. Due to the amount of people in such a confined space, I thought it best to leave.

(From field notes)

The consultant 'slit her throat', quite literally, and it is probably the most accurate way to describe the procedure, a percutaneous dilatational tracheostomy. A fair amount of force was involved, pushing curved blue plastic 'sticks' into Dottie's neck using rods of increasing sizes that were slid over a guide wire to open up the neck; what is technically termed a modified Seldinger technique. There was an element of display, of performing 'being an intensive care doctor' for the audience, but then for the benefit of the students, it was a far more entertaining version of the classic lecture theatre presentation that has a couch in the centre or table in the classic depiction of an anatomy lecture (see illustration below of *The Anatomist*). Dottie had become a tool of education, but as part of the procedure as with many surgical procedures, the task is performed on the body, not the person, the person remains hidden through various screens including the curtains. Interesting though the performative ceremony is, and the multitude of interpretations that could be made of it, the mouth has again reappeared as a site of contestation. Instead of a political wrangle between the anaesthetic department and intensive care as witnessed in Chapter Seven, this time it is about Dottie the 'serial extubator' as she was referred to by the intensive care consultant and the danger she poses to her self, her survival. For Dottie presumably, the battle has been won, her mouth is free of the tube and the tapes that secure it, now the tube has been placed in her neck and as far as the intensivist is concerned the problem should be solved.



Picture 8.2: Vesalius the anatomist.

As part of the surgical process Dottie was also constructed as an ‘educational tool’, with a host of students and members of staff watching the ‘master surgeon’ at work, displaying his supremacy as he dictated what it was he was doing for the benefit of the assembled audience, whilst cloaked in the surgical accoutrements of mask, gown and sterile gloves. The tracheotomy tube is tied into place with soft foam tapes, Dottie is conceived of as the rebel, having ‘self-extubated’ her endotracheal tube on numerous occasions so the tracheostomy is performed, which was later sutured for ‘security’ as we will see. But again, even though the problem appears to be solved, Dottie is still trying to remove the tube, but this time it’s the tracheostomy tube. The greater the risk that Dottie poses to herself, the greater the potency of technologies introduced to contain her behaviour. The strategies that intensive care can introduce can rise exponentially to meet the demanding nature of behaviour. The more Dottie tries to remove her tube, the greater the likelihood she will require increased sedation and surveillance. At the time of the Dottie’s admission, there were no physical restraints used within intensive care. Since Dottie’s admission, steps were taken through the hospital legal team to introduce a physical restraint policy, so that patients like Dottie could have their limbs tied to the cot side or the side of the bed. However, at the time of Dottie’s admission, only what is termed chemical restraint was the technology available for use within intensive care in addition to physically holding

Dottie's hands which took staff away from work elsewhere. So Dottie had been re-intubated four times in total before it was decided that she would require a tracheostomy, the other technologies had failed, the *ante* had needed to be 'upped'.

Consultant: What's she sedated on

Staff Nurse: Propofol

Consultant: I know she's been pulling at her trachy, but I don't want a sedation score of 5

Registrar: A sedation score of 5

Staff Nurse: NOT a sedation score of 5, preferably around 3

(From Ward Round)

The sedation continues, even with the tracheostomy in place. As with any patient in intensive care it runs as an infusion that the nurses titrate to a set sedation score, which is generally set by the consultant. Within intensive care they use the Ramsay Sedation Scoring system, which is a scale from 1 to 6. It is depicted on the observation chart:

- 1 states 'Anxious or restless or both' referring to aggression or agitation;
- 2 would represent a normal waking state ('cooperative, orientated and tranquil' as it appears on the chart);
- 3 is a sort of rousable drowsiness ('responding to commands');
- 4, 'brisk response to stimulus' represents normal sleep;
- 5 'Sluggish response to stimulus' which suggests that the patient is heavily sedated;
- 6 is 'No response to stimulus' or unresponsive.

(Adapted from Intensive Care Observation Chart)

Dottie was wavering between 1, 3 and 5, at the time of the above Ward Round her sedation score was 5. For the intensive care consultant she was too heavily sedated, the staff nurse dictates to the registrar the sedation score he can work with, and he wants Dottie drowsy. Usually the 'special instructions' section of the chart is left blank, but Dottie's consumption of sedative drugs has gotten a bit out of hand, so the parameter is set for 2-3, co-operative or responding to commands only. For the nurse, the difficulty is in finding the balance between Dottie being awake and attempting to remove the tube and being 'flat' or sedated and is discussed in relation to the sedation scores, so whilst the consultant has no preference apart from not a Ramsay score of 5, the nurse tells the registrar what he wants prescribed. But by the afternoon, Dottie had removed her tracheostomy tube which the consultant 'clunked' back into position. The banal heroism (Zussman, 1994) involved in 'sorting out' the problem (Dottie) by the consultant was displayed to the attending ward round, even if 'down-graded' to some extent by the comments of Dave, the staff nurse, who clearly viewed this as a

consequence of reducing the sedation. But this balance was not found as the recording of the evening Ward Round Testifies.

Harry [Intensive Care Consultant]: Erm, today (.) *lunchtime today (.) she had her sedation weaned off and stopped (.) and tried to pull her tracheostomy out and then she was choking*
Dave [Staff Nurse]: *That's hardly surprising really.*

Harry: And the cuff was deflated and the team [of nursing and junior medical staff] who were at the bedside couldn't put it back in (.) applied the face mask and got the bronchoscope down it was in the trachea so 'CLunk', *pushed it back in and made sure it was right in the trachea and sutured it back into place (.)* So that was alright (.) And we've re-sedated her with propofol and we've added clonidine for her agitation (.) Em basic plan on that side of things is keep her quiet until tomorrow and then we assess

(Evening Ward Round)

However, the tracheotomy tube like the tubes before them had been removed by Dottie. The consultant, who had performed the tracheotomy earlier and was still present for the evening ward round, replaced it. This was sutured in place which was unusual for this type of tracheotomy and was legitimated through calls to 'risk'. The following morning ward round saw it explained away as a form of heroism, as he 'clunked' the tracheotomy tube back into place as the nurses and junior doctors looked on helplessly. Not only was the tracheostomy tube 'clunked back in', but was sutured in place for good measure. As the risk Dottie poses, so do the technologies available within intensive care to circumvent these risks. But the risk is not just about self extubation, which for the nurses is almost inevitable given the small amount of leeway they have between protecting Dottie and sedating Dottie, between allowing Dottie to act autonomously, and keeping her sedated. However, for the nurses, suturing the tube in place may not be the answer, as it was perceived as a way of causing more trauma when she (inevitably in the nurse's opinion) removed the new tube. The consultant's decision to 'minimise risk' was countered with the nurses observation that it would 'maximise trauma'. The consultant returns in the afternoon as the Ward Round at the time recorded:

Consultant: ...so there we have her (.) this plan for tonight is just keep her quiet and STop her pulling that tracheostomy tube out (.) I've sutured it in to try and minimise the risk of that

Staff Nurse: or maximise the trauma ((laughs))

Consultant: [or maximise the trauma

Senior Registrar: so it will be worse] when she pulls it out

((general laughter)).

(From Ward Round)

Dottie is being silenced and the strategies of silencing are increasing. As far as the intensive care consultant is concerned, she needs to be kept quiet, presumably he does not wish to spend his time re-inserting tracheostomy tubes. The 'writing up' of Dottie

has neglected other aspects of social life through focussing on the talk constituted around her and those technologies which impact upon her. Whilst the actions performed around Dottie are focussed on what has been presented is only what Dottie is doing which intensive care staff consider to be a danger, in part because Dottie is read as a danger, a risk. This has been the case with some of the accounts in the previous chapters, such as Roy and Albert. What has become apparent is that, even when written in a certain way, using field notes and field recordings, the performances of these patients provides a very rough insight into who they are as persons. The point is that intensive care patients are performing social at times through extension to cultural materials (Latimer, 2004), such as a ventilator or endotracheal tube, to other persons such as between Roy, Albert and the two nurses, or through their actions. But these connections to others and ways of seeing these patients is only one of multiple means through which they are seen and make themselves visible socially. To some extent, this is how they are seen by the intensive care staff, through the cultural materials, through their actions, but it is only a temporary view which is subject to change at any given time. The intensive care unit is characterised by vulnerability and passivity, but through this, it becomes clear who these critically ill people are. For the nurse in charge of intensive care, when handing over to the next nurse in charge at the end of the night shift on Dottie's eighth day of admission, she is read quite specifically:

Dottie, what a star ((giggles)) we are to encourage diet this morning. Sally [the nurse] was not afraid to go near her, she said Sally wasn't qualified to look after her. She said she feels claustrophobic when people are in the bed area, especially at night. I don't know about this lady, there's something going on there.

(From recording of handover between senior nurses in Sister's Office)

Dottie has been read as a 'star' there is something 'going on', an intuitive something wrong with Dottie. She has been refusing certain staff coming near her and is being able to 'choose' which nurses she wants around her, which for the more junior staff is another reason why Dottie is so demanding. After countless attempts at removing tracheostomy and endotracheal tubes, some of which were successful, the staff of intensive care no longer know what they can do for her. However, it is still the case that Dottie is being presented from just one perspective, she has been written up as challenging, as a danger, as a risk and a great deal of this has come from issues surrounding her mouth and the tubes. But perhaps there is another side to Dottie which will be presented in the following section.

(Re)Presenting a 'Star'.

In the closing section of this chapter I aim to present Dottie, or re-present her from a slightly different perspective, Dottie as her family see her in intensive care. As previously alluded to, Dottie is read in relation to her actions. Actions which, given the serious nature of the consequences, are highly problematic for intensive care staff and they could be forgiven for taking such drastic steps to ensure her integrity as a survivor of intensive care. It is after all, for intensive care, 'in her best interests' to not kill herself. Her behaviour is challenging, not just because of the serious consequences, but because it challenges the very fabric of what intensive care is about and what the intensive care staff are trying to accomplish, which is to dispose of her to the ward. Through her disposal, which for intensive care is ensuring that Dottie is well enough to return to the ward and eventually to return home, intensive care has played its part in ensuring the continuance of Dottie. As intensive care by its own definition, exists for patients 'with a potentially recoverable disease, who require more intensive observation and treatment than is available on a general ward (Intensive Care Society, 1997), then not only is her behaviour challenging to the staff who are trying to get her over the current patho-physiological crisis, but challenges the very nature of intensive care's ethos through her refusal to accept the more intensive observation and treatment. For intensive care to function, it is contingent upon Dottie allowing these things, intensive care, to happen. The question which was never raised was whether she actually wanted admission in the first place. This is something that cannot be answered for reasons that will become clearer, however, it is important to gain another insight into who Dottie is and perhaps hint toward why she is so challenging.

As part of the consent process, I introduced myself to the family and gained assent to observe interactions around Dottie and interview her on discharge from the ICU. They informed me that she loved to talk about her illnesses, it is in fact one of her favourite pastimes. She is a 74 year old lady, who lives at home with her husband; for the past few months she has had trouble with her breathing, sleeping a lot during the afternoon and only able to walk short distances without getting out of breath. She is a regular visitor to the local GP, and hoards vast amounts of drugs in the bathroom, changing her GP when she doesn't get the drug she wants, or if the GP stops prescribing them.

She was described by her daughter as an awkward woman, not afraid of anything, and demanding when she didn't have what she saw was her right. Her husband was her soft spot, although she would shout at him, perhaps more than anybody else, she was as in love with him now as she ever was. Her family came in whenever they could, her daughter worked unsocial hours, and was not always able to visit, for which the husband routinely apologised on her behalf each day he came in. She loves to talk they told me, usually about her illnesses, and about the pain from her arthritis. She had two children, a daughter and a son, the son died a couple of years ago, and she has suffered with some degree of depression since, her daughter remains very close, she lives nearby, and they keep in regular contact.

“Hello there, how is she”, Dottie's husband enquires, I say nothing, Dottie has been watching him since he walked over to the bed area. He walks over to her, she puts both arms up in the air and pulls his head toward her and gives him a kiss. He sits down next to her; there is a cot-side on the side of the bed, used to prevent patients from falling out of bed. He rests on this barrier, and tells her about what is going on at home, her daughter will be in tomorrow as she has to work double shifts at the police station and is unable to visit. He stays sat still, leaning over her via the cot side, she coughs, shakes her head, closes her eyes and goes off to sleep.

(From field notes)

Walking into the bed area after Dottie has had her (sutured) tracheostomy; she wakes from another bout of anaesthesia. Her husband greeted me at the foot of the bed, and asked how Dottie was; I suggested he spoke to the nurse sat next to me who is looking after her. I had become a feature of intensive care and a presumed source of information for the family. The nurses by this time had become quite used to allowing her greater arm movement, she had after all not attempted to extubate herself for a while; the couple sat and talked (or rather, her husband talked whilst Dottie mouthed). The following day I had another chat with her daughter: ‘oh, she can be quite difficult when she wants to be, you just can't make her do anything she doesn't want to do’. I could fully appreciate that and the family created a picture of her that was quite unlike that of the intensive care staff. In many respects the story that the family created legitimated Dottie's behaviour as legitimate for Dottie. Dottie was ‘doing being Dottie’, but for health care staff there was no place for this; performing identity when it does not fit with the efficiency and safety of intensive care could not be accepted. For Dottie's husband, his wife could be difficult or ‘obstreperous’ as he put it, but still the woman he loved and the woman he married about forty years ago. But for health care staff she was viewed quite differently, whilst there would be agreement that she could be difficult, the ICU staff saw her as a danger to herself, a threat to her own

physiological integrity. When it was decided that a tracheotomy was to be performed she had no say in what was to happen to her, the subject of Dottie was transformed into the object of treatment, of self-damage limitation, with no right to reply. When watching the staff around Dottie, one would be forgiven for thinking that they are implicated in Dottie's behaviour, setting the conditions for her actions. Dottie is again transformed into an object of concern, an object of pollution and an object of risk. She needs to resign to the program (Latour, 1991) of intensive care.

The ward round stands at the foot of Dottie's bed. I stand next to the bed listening and watching. Dottie sits up and looks at me; she has been disturbed by the talking at the foot of her bed. I explain that it is the ward round as she looks at me. The staff nurse looking after her walks to her right side and talks to her, the side her hearing is poorest. She is sat semi-recumbent, with her right arm resting on the bed's cot-side, like a lorry driver resting on the side of his cab. Her left arm is resting above her head. There is some 'goo' in her mouth, the nurse sucks it out, not speaking to her, Dottie just lets it happen, and closes her eyes. She told me about the discomfort the tube was causing; demonstrating that it restricted her movement and urged me to sit on the left side so she could hear me. She sat with her arm hanging over the side of the bed; to me she looked like a truck driver with her arm out of the window, surveying all that was going on around her from the safety of her cab/bed.

(From field notes)

Admission to intensive care from a general ward can be more emotionally challenging for patients, particularly when they are admitted in a state of unconsciousness, than any other mode of admission (Perrins et al., 1998). Whilst this in itself is not part of the critique of Dottie's admission, it does offer a context to her experience, or perhaps more tellingly, her behavioural accomplishments and the interpretation of this by intensive care staff. The tight fitting mask was applied to Dottie's face soon after admission, something that she would probably not readily have consented to have applied to her were it not for the acute deterioration in her physical health. Dottie's moribund state allowed treatments to be performed which initiated her into a new role as intensive care patient, the insertion of lines for treatment or monitoring, the use of the mask and later intubation, the visual representation of her patho-physiology (Place, 1999). Dottie has been ordered, her internal organs made visible (Foucault, 1976) albeit as a representation, she has been opened out through insertions of venous lines which ease the access of necessary drugs. She has been processed, made 'intensive care friendly' for the staff, yet she remained for the most part 'intensive care unfriendly'.

So what is there to say about what is happening with Dottie, how can this be theorised? It is clear that Dottie is accomplishing something, far from the socially

dead object which is often perceived to be the lot of the intensive care patient there is something happening in this account of her. This is an area of performativity that shall be addressed later, for now there are particular insights into how the technologies of intensive care are intensified, arguably to eradicate the social, yet fail (Rapport, 1997). As Dottie spent greater time doing being herself, in Latour's (1991) sense the anti-program or those behaviours which are seen to be problematic and require control, the program of ensuring that Dottie fitted the remit of an intensive care patient were intensified. Just as in the strategy Latour's (1991) hotelier employed in order to keep the room key within the hotel, such as warning signs and the addition of a heavy weight to the key ring, so the program of intensive care intensified in order to ensure that Dottie kept her endotracheal tube in place. Whereas the hotelier creates technologies in which the keys remain, for the most part, within the hotel, or the strength of the program overpowers the anti-program, there can be a point where a few lost keys are not worth the hassle of introducing new technologies. For the intensive care clinician, this attrition cannot be acceptable as human life is at stake. Indeed, for the clinicians the anti-program of Dottie doing being Dottie had to be removed and so after a week she was transferred to another hospital, legitimated through calls to 'expertise in the weaning of long term intensive care patients'. It could equally legitimately be argued that the anti-program of being oneself is too much for the technology to control, or at least control humanely, as opposing forces of pharmacological restraint in the form of anaesthesia come to the surface. In either event, the durability of intensive care as an organised and organising technology demonstrates its durability as a technology in ensuring Dottie's exit, irrespective of the power of the individual.

Through Dottie we get closer to an insight of what constitutes intensive care through its accomplishments. Dottie regularly breaches the reality of the culture of intensive care as perceived by those who hold it as a working environment (Garfinkel, 1967). Through her voicelessness and through her challenge to those things that inhabit her mouth, Yankeur suction, endotracheal tubes, the silencing of intensive care technologies, Dottie can be seen to be breaching the given social order of intensive care. Perhaps more clearly through Dottie than through the other examples from the ethnography so far, the moral order of intensive care is exposed, made visible to inspection. As the mouth is so tied up with intensive care practices on the level of

things sacred, civilised and civilising through talk, it is also bound up with risk, pollution and the taboo. It is a space of ambivalence, as is intensive care and through Dottie we come to see how intensive care breaches orality. In part because of this breaching Dottie finally becomes an object of disposal, to another intensive care unit.

Chapter Nine.

'Drawing Up' Intensive Care: a discussion.

As Chapter One symbolically performed a 'laying out' ceremony to a piece of research which, for numerous reasons, was never performed, this discussion aims to draw the thesis back together, to make it whole again. The major themes that, whilst not always explicit, thread throughout the text will be brought back in, bound together. In part, this explains the unorthodox nature of this thesis from the beginning through to the end. Having located the thesis and introduced it, it is then labelled as dead, as non-existent. A theoretical position is put forward as a means through which the thesis could be understood, but it does not detail all of the major theoretical positions from which the thesis arises. It creates 'partial connections' (Strathern, 2004) between different aspects of the thesis and leaves others unwritten, concealing and revealing itself as it, in turn refers to the concealing and revealing work of cultural production. A bit of history is invoked and then placed next to a local history of the research environment, this in turn is melded with popular representations of what intensive care might be accomplishing within a cultural imagination. A methods chapter touches on some issues related explicitly to the research, some that relate back to the original theoretical position, and then returns to 'writing up' an ethnography. A 'trip through ethical approval' methods section is claimed to be an opening empirical chapter, recast as an auto-ethnography, but is then left hanging in space with no analysis or discussion of its reason for being, untouched and incongruous against the following ethnographic chapters. Within the methods chapter, it is suggested that these chapters are based upon accounts of the critically ill, families and staff members. However, these chapters do not invoke very much in the way of interview material, the patients rarely speak and yet a sense of who they are as persons emerges. The chapter concerned with the unconscious body relays more details of other things happening around the body. The chapter concerning two elder gentlemen, who may have had a joke, discusses the placement of a sink, or a bin. The next chapter purports to be about the mouth but discusses effacement and strategies of performing social that do not tie in with the social aspects of the mouth. As a result this discussion will be slightly unorthodox, and as such it will remain consistent with the rest of the text in this. The aim of this discussion chapter is to run through those major themes that tie

what may appear to be a piecemeal approach to writing ethnographically into something that makes a great deal more sense, and, it is argued is so much more powerful as a piece of ethnographic writing as a result.

Through examining a given culture of intensive care as a distinct space and bringing forth encounters with a Local Research Ethics Committee (LREC), a number of issues have emerged which will form the structure of this discussion. What will be discussed first are the cultural materials, objects such as charts, signs bed-sides, histories, as well as performed displays such as turning away, closing eyes, joking, berating and the ways in which these materials are mobilised as part of a performance of persuasion (Munro, 1999). A given identity such as senior doctor or nurse, ethics committee member or loving wife is being performed in relation to these cultural materials and has an effect on those who witness the performance. These displays are performed to a given audience, such as myself (non-member) or colleagues (members) for example, as a partial means through which a given cultural position can be emphasised and cemented. It is through these subtle moves of relations of power that the cultural accomplishments of a given member can be made visible and this is a particular theme that is woven through the thesis. Notably, the performance of such culture can be witnessed through these cultural materials and made explicit through relations of extension (Munro, 1999; Latimer, 2004; Latimer & Munro, 2006). The perspectives within this thesis have switched from one to another in order to make visible certain cultural assumptions. In turn these cultural assumptions (artefacts) through their partial connection (Strathern, 2004) make visible a certain cultural order and this thesis has played with this idea throughout.

The accomplishments of intensive care can be witnessed in relation to its self-definition. This definition is its criteria for admission, and this definition of itself locates intensive care within a particular historical context such as the Copenhagen polio epidemic, a context of durability that (apparently) seamlessly recreates itself in the present, separating itself from competing accounts as a particular discursive formation (Foucault, 1972). Once established, this discourse becomes (almost) the only way that intensive care can be viewed and, as a consequence, practised. In turn this has powerful effects upon who can be admitted to intensive care and who may be legitimately disposed of. As an organising and organised discourse, intensive care's

definition of itself provides a certain cultural cohesion for its workforce; it is a production of doing membership. However, such a cohesive discourse in turn creates a space of division, of otherness, of those not appropriate for admission. The non intensive care members of the rest of the hospital population are recast as other. The history of anaesthesia from which intensive care has such a close clinical and historical relationship, is rendered marginal and even effaced, becoming 'excess baggage'. Yet intensive care medicine is a developing speciality which in most European states requires qualification in anaesthesia as well (Burchardi, 2001), in such regards it is dependent upon anaesthesia as the majority of practicing intensivists (at least in the UK) also have training as anaesthetists, which in turn has particular effects, such as those witnessed between open and closed intensive care units (Chapters Three & Seven). Intensive care can be seen as an accomplishment of durability (Latour, 1991), creating a particular space from which it is understood and this space, as was demonstrated in relation to the popular cultural representations of intensive care is extremely powerful, carrying the consultants beyond the confined space of the operating theatre. These cultural representations aim to heighten the seriousness of the mundane social performances of intensive care.

Aligned to this idea of durability and of doing member (as just noted), is an idea of disposal. The body and the LREC application can be disposed of physically or metaphorically (Latimer, 1997), but such a disposal cannot be performed wantonly. Disposal, it is argued, is an effect of non-alignment, of resistance and of difference; it is a deferral or *différance* (Derrida, 1984). Inversely, passivity, acceptance and concordance with a given regime is sought, promoted and rewarded (Bauman, 1994) and as a result, difference becomes a real and inconvenient threat to the integrity of a given regime or system. The issue is made visible when the given order is breached (Garfinkel, 1967) and these breachings, such as refusing to forego a theoretical position within the research and refusing to be a passive patient, can result in such disposal (as made visible by Foucault (2001, 1991)) through the direct challenge perceived by those representing control of a given cultural order. However, such a cultural order is subtle and its power derives from its subtlety. The performance of disposal or *différance* is achieved through a performance of persuasion, and this is legitimated through calls to a durable material such as a blood result, a chart or a specific occasion of risk such as self-extubation. This casts whatever does not

conform to a local cultural perception of durability as other. Once made other, or othered, the disposal is legitimate (Bauman, 1994; 2000), even if the otherness was created through a challenge to, or discordance with, a cultural system, such as a definition of intensive care or an unusual research project.

The argument espousing a refusal to separate the ontological and epistemological has been rehearsed throughout this thesis and will be alluded to more than re-invented. It is argued that it is one of the legitimating factors for the *différance* of the research from the position of the LREC in the preceding section of this discussion. As such, it is a methodologically related feature that will not be re-engaged with. What this section will detail is its particular form of engagement within the cultural space of intensive care. As has been seen in the accounts of the intensive care patients, they are not asked 'how does the organisation and practice of intensive care impact upon you', but are witnessed in the 'mundane everyday' practice of intensive care. Issues are not examined head on, but to the side, accomplishments are not asked for explicitly, but emerge at an obtuse angle (Strathern, 2004). It is the notion of a deliberate imprecision that Law (2004) invokes that bears witness to these cultural practices. The cultural practice of intensive care emerges through extension to the materials of intensive care, through its relations to others, through disposal, through cohesion, through membership. It is this aspect of the production and reproduction of the culture of intensive care that emerges and it is through this that the accomplishments of intensive care can be made visible. These accomplishments are referred to within previous sections of the discussion, the focus of this section is on how these cultural materials, performances and persuasions have been examined.

'The relativising effect of multiple perspectives will make everything seem partial; the recurrence of similar propositions and bits of information will make everything seem connected... Partial Connections require images other than those taxonomies or configurations that compel one to look for overarching principles or for core or central features.'

(Strathern 2004, p. xx)

For the most part the thesis has attempted to present a multitude of perspectives about what intensive care accomplishes and some of this has been related to issues concerning ethics. Intensive care has been presented in terms of its relations; to itself, to the media, to its patients, to anaesthesia, to nursing, to history and so on. What the concluding section of this discussion chapter aims to accomplish is to re-invoke an

issue laid down at the beginning; that of intensive care as critical site. In particular, the space of intensive care will be discussed. As witnessed through 'performing' the ethnography and represented through 'writing' the ethnography, it is a place, of physical stuff, a concentration of technological and human 'resources'. It has erected boundaries, both physical and metaphorical, between itself and 'elsewhere', but these boundaries are being breached by its inhabitants, they can now take intensive care out of the space, to other hospital wards, to other hospitals, but the doors are often closed to others who wish to enter unless it is on 'intensive care' terms. It is a space of metaphor that for the most part is in relation to a proximity to death; a metaphor for mortality, the space between life and death. Further, it creates new taxonomies of what constitutes death, cheating an age-old distinction between life and death. Its self-definition is concerned with access to the space and the legitimacy of that access, not simply of entering a place, but of who should have access to treatment and, with bed limitations, ensuring there is not a 'waste of space'. Within intensive care are numerous blurred spaces between body and machine, between a patient and the individual performances of 'everyday' social life (Rapport, 1997). It is a space of drama and of hope. It is a space that creates multiple others, it is an accessible and non-accessible space and you are directed by signs, by talk, to perform in a certain way in this space. The intensive care unit no longer exists, yet remains a space of invocation and of alterity, of power and powerlessness, of contradictions and the final section emphasises the significance intensive care as a particularly critical site.

Drawing up Critical Materials.

Chapter Six begins with an account of gaining access to intensive care, of the processes involved in becoming a legitimate intensive care patient. As part of the admission of a patient from the operating theatre, the intensive care nurse concentrates upon 'sorting out the body' through which the transferring operating theatre nurse is marginalised, made less important. The body of the patient and its relation to the monitoring equipment become a distinct feature of the nurse's attention. They are invoked as materials from which the accounts of the transferring nurse are made marginal to the materials of body, monitoring and ventilation, a process of embedding through a processing of the body. The materials become a display of engagement; this is particularly significant given the divorcing of 'intensive

care' from the 'operating theatre' as presented within Chapter Three. In the same vein the operating theatre nurse invokes the materials of 'her' chart to emphasise that which is significant from her side of the patient's story. But this side of the story and the materials through which the story are invoked are within the realm of other and, as a consequence, within intensive care they are perceived and enacted as less significant materials. The materials display an aspect of the divorce of intensive care staff from the operating theatre, it is no longer a space in which anaesthesia and nursing are confined, they have broken free to create their own space of intensive care, the old materials of legibility, of tethering, have no place within intensive care. Paradoxically, the materials invoked by the anaesthetist are part of a language that can be aligned with, even though the anaesthetist and his role is associated with the operating theatre. Those issues of ventilation, sedation and cardiovascular status are the daily materials of significance for intensive care and, as such, become legitimate materials of engagement, despite the space of misalignment.

Materials produced by one party can also be enrolled by another. This was tacitly introduced in relation to embedding an intensive care admission (above). For example, medical staff within intensive care can enrol a given material such as a nurse's observation chart. This is sometimes taken from the nurse during a ward round in order to demonstrate a particular point about a patient's physiological status. Much like the Zimmer frame of Latimer's analysis (2004), a 'belonging' of a physiotherapist is taken by the doctor and placed in front of a patient on the ward round. His fear of falling prevented him from walking, such a 'resistance' to standing and walking is countered within a discourse of 'you want to get better don't you' as a specific point of alignment, bringing forth a symbolic and easily transferred and translated material that cannot be escaped from; the Zimmer. However, the very fabric of the nurses' work in the form of the observation chart was to be done away with under the notion of a paperless intensive care unit and replaced with a computer (Chapter Six, *Bodies lost in Translation*). The charts are a material that focus the gaze of the nurse every hour, and it is through this that I argued that the body is made legible, as a temporal record, as a physiological representation (perhaps more accurately, as previously noted, an interpretation, a cultural artefact) and significantly a chart which requires translation by the nurse to others.

These charts are materials that are produced and are often specific to the nurse who produces them, there is colour coding, bracketing and specific means of including running totals that can be quite idiosyncratic, but generally legible to the nurse. Making the observations computerised and thereby having a general level of legibility, in part takes away some of the specialised, although quite mundane, nature of the intensive care nurses' work. The mode of organisation of the nurse centres around a particular production, a production of an almost profession specific material on account of its degree of legibility, unlike the broader cultural legibility of the Zimmer. When the nurse is no longer required to translate the chart, the process of 'her' work is made more visible, open to scrutiny and auditable, an alignment to a particular discourse of efficiency and transparency. However, the power the material has to organise the practice of the intensive care nurse, and indeed the Ward Round was lost when the paper (almost) disappeared, emphasising not so much the strength of discursive alignment that Latimer (2004) invoked, but the organisational power of the everyday material through its removal. In part owing to the idiosyncratic nature of the material a particular reading of the nurse's identity is attempted to be read through it, such as Sister's account of Clive's (Senior Staff Nurse) bed area (Chapter Eight).

An arterial blood sample as a specific material can be invoked to settle disputes over an appropriate point to extubate a patient, or alter ventilatory settings. As noted in the section of Chapter Six (Bodies without meanings), the nurse as part of an assemblage of materials, often produces the result sheet. The assemblage of materials is not meant to refer specifically to a particular Deleuzian reading of assemblage (DeLanda, 2006), a break from the local and the global against the totalising breadth of scale in analysis. Although this is tacitly referred to in relation to the idea of 'plugging bodies in' (Chapter Seven) and has been invoked in relation to Strathern's (2004) notion of amplitude (Chapter Four) and will be further discussed. What is significant about the assemblage of materials and their invocation in the production of a certain outcome is that they can be dismissed. Materials can be used to play against other materials, such as the patient looks 'knackered', 'tachypnoeic' (a fast rate of breathing), agitated, sweaty, which in turn enable other materials to be disregarded. The body of the critically ill is invoked as a material and a material that challenges the 'factual' representation of a chart or blood gas result. In part this demonstrates the partial and contingent nature of the materials that can be read as factual representations of

physiology, but are also cast as an interpretation of the body to produce a particular effect. A 'performance of persuasion' (Munro, 1999) is often invoked by medical staff, particularly consultants, whereby a material is incorporated or dismissed outright, yet when the nurses invoke similar materials (as in Chapter Eight with reference to securing a tracheostomy tube with a suture), the material as performance of persuasion turns from an objectifying display to a display through humour.

Consultant: ...so there we have her (.) this plan for tonight is just keep her quiet and stop her pulling that tracheostomy tube out (.) I've sutured it in to try and minimise the risk of that

Staff Nurse: or maximise [the trauma

Consultant: or maximise] the trauma

(From Ward Round)

The physical material of the tracheostomy tube is produced through a call to risk, but this risk is challenged through a countervailing call to trauma. This demonstrates the subtle difference of membership within the culture of intensive care. The nurse and the doctor may invoke the same materials and have a similar understanding of the place of the materials but the difference is within the deferral; the consultant can disregard or defer the information, but the nurse has to defer to the position of the consultant. In part the relative order of the social is demonstrated through the display of the material as a performance, emphasising the relative authority of the membership. The place of Dottie is simply reproduced as a material to be worked upon, somewhere near the bottom of a hierarchy of who's who within intensive care. But, then, this positioning of Dottie within a given hierarchy is still quite inaccurate. It is more that a given material gains prominence in relation to alignment with a particular point, argument or discourse. Dottie can be similarly held to be a strong point of alignment or a weak one which could be read in terms of a hierarchy, but if it was it would be a hierarchy of flux and change and as a consequence not a hierarchy at all, but a specific strategy of allegiance. For Latimer (2004), the alignment of cultural materials and social processes, such as accounts of Dottie in this instance, are what helps the accomplishment of particular power effects.

Within the meeting with the ethics committee (Chapter Five), the woman whose daughter was in intensive care invoked her situation with her daughter as a particularly powerful material. From that point the discussion of the research came to a stop (Latour, 1987), the material invoked could not be argued against as the material related to the suffering of her and the suffering of her daughter. There are times when

a particular material can be invoked as a device to halt any other discursive alignment from being possible. To argue against her position would be to make light of her experience and that of her daughter, a situation is invoked as a specific material that has a specific use which is to prevent any further discussion on the matter, and it has to be closed down. Through an alignment to human suffering using her and her daughter's experience of intensive care, any means of countering this alignment, or a shifting of this discursive formation becomes an effacement of her and her daughter's experience. Through this invocation, this alignment to her own and her daughter's suffering, an account of the intensive care patient as effaced is produced and reproduced.

The critically ill have been re-categorised, through the account of the ethics committee member and mother of a daughter who was in intensive care, as having no memory and therefore nothing to say about the subject and, as such, to try to engage with them about this period would be to pointlessly wound the critically ill once the period of trauma had ended. Accounts of critically ill patients are drawn through the family and as a consequence, their story (suffering) is not worth listening to, to suffer requires a 'turning away from', a denial, a position which is in a small way similar to that of survivors of the holocaust (Levi, 1999; Wilkinson, 2005); suffering as an effacement. As strategies of silence and silencing have come to form an important thread throughout this thesis, through this particular account of 'protecting the daughter', another strategy of effacement is made visible. In this sense, intensive care can be read as a technology of effacement, of silencing and through 'protection of the critically ill', the ability to talk about this suffering is reduced and the strategy of effacement spreads beyond intensive care. What was held to be important from the beginning of the research was this idea of effacement. Among patients who have had an acute coronary event such as heart attack who have spent prolonged periods of time within the hospital, family members found reflection on such a time difficult to talk about. For the patient once they had recovered they wanted to 'fill in the gaps', to make sense of the experience but in many instances this was denied to them (Johnson, 1991). As demonstrated within the thesis, the performance of being a mother to a critically ill daughter is such an occasion whereby any threat to this silence is countered, and countered vehemently.

This was not the only strong performance of authority within the ethics committee. Professor Jones refused to acknowledge the research as an ethnography in the first instance, unsettling the position of the research. 'It doesn't look like any ethnography that I've ever heard of', was his position, presented as a voice of reason, experience and authority. The material of the ethnography could be dismissed instantly and any discussion of the ethnography would be counter to his position, a position of stability and authority. To engage would be to unsettle, but the strength of the position within a room of colleagues who are convinced of his authority on such a matter would be a matter of face work, to lose face or to save face. The position became one of right or wrong, with nothing in between, the single answer to the question (Chapter Two); against Strathern (2004) there are overarching principles and this is the only way that ethnography can be performed. It was reinforced in the rejection letter which emphasised his willingness to discuss the nature of ethnography with myself and my supervisors, revising the ethnography to one that fits with his conception of what exactly ethnography is. The material (the research) was invoked as part of a display of authority, of right and wrong, and one that not only I could learn from when meeting him, but my supervisors could also learn from his experience of what ethnography is and how exactly it should be performed. Within the committee, his sovereignty was durable; the role of other was to bow down to his performance of knowledge invoked through the material of the application form.

When Professor Jones invokes such materials as experience, his position within the committee is made visible and it is something that holds. This has been related previously to other materials such as charts, results sheets, discursive alignments and the performance of a Ward Round, which have been presented as different forms of cultural materials and social processes that can be invoked. The material is not just the physical 'stuff' but also the ideas that are made visible through a given performance; materiality is in part the physical materiality that invokes something and those non-physical things that similarly hold persuasive power (Latimer, 2004 drawing on Strathern, 2004). What I am getting at here is that allegiances are made which, as a result, give an insight into a given position; the materials through their invocation can be seen as part of an accomplishment, the argument or position is made visible through the materials invoked to support it. However, these positions and these materials are subject to change and revision. What was held as strong or durable in

one sense can be down played in another. This has something to do with accomplishment, not just those things that occur as a result of some performance of social and allegiance to a material that holds, but to do with what accomplishment is desired, and demonstrates the relative authority of those performing an invocation of the material. It is bound up with expediting a certain action and making that action legitimate. To discharge Dottie to another hospital (Chapter Eight) as it is in her best interests, to alter a system of documenting vital signs, to suture a tracheostomy tube in place, to refuse interviews with intensive care patients, to correct a definition of ethnography and so on are about legitimating action. This legitimacy is performed and this performance is made through recourse to materials, and these materials are invoked as they hold; they cannot be argued against. They make visible authority, but the authority has the power to alter and change those materials to fit the nature of whatever the authority wants expedited and, as such, it becomes bound in with a performance of persuasion (Munro, 1999). It is these accomplishments that the following section will explore.

Drawing up Alterity through Disposal.

What has been attempted in the previous section of this discussion is to look upon those materials that are invoked as part of a performance. In part the previous section has demonstrated the heterogeneous nature of such materials, beyond the purely physical and into the realms of the durable. The invocation of these materials can be read as a means through which social action can be legitimated and, as a result, can be accomplished. This section, drawing on the ideas put forward in the last section, focuses upon processes of othering, of alterity and the legitimation of disposal. Following Derrida (1976), it is through the other, the 'what is not', that things are made visible. Similarly for Goffman (1982), self is understood in relation to performance with/through another. Using these ideas, this section traces that which intensive care deals with as self and that which it deals with as other to get a feel for what is, or what should inhabit intensive care. Through this section of the chapter such accomplishments will be discussed in relation to such disposal.

Dottie was presented in the closing section of Chapter Eight in relation to the idea of the program and the anti-program of Latour (1991) and in breaching the order of

intensive care (Garfinkel, 1967). She was disposed of to a place that ‘specialises in weaning patients from long-term mechanical ventilation’, a neighbouring intensive care unit that had become part of the Chief Consultant’s responsibility (as discussed in Chapter Four), a unit regarded as a ‘lesser ICU’ for the purposes of performing this research. But Dottie could also be perceived as other, of not following the program (Latour, 1991), not fitting the order of *this* intensive care (Foucault, 1972), not fitting the classificatory system of a *proper* intensive care patient, her conduct was read as *disorderly* and as such Dottie became amenable to disposal.

However, it is not the conduct of Dottie that legitimates the disposal; it is the idea of ‘acting in her best interests’ that legitimates the move. This can be seen as an ethical principle that holds, and is invoked as a specific material from which such a transfer to another hospital is legitimated and revealed. The underlying tensions of her being ‘difficult to manage’, of her being a ‘danger to herself’ and of the necessity to find experienced staff to be allocated to ‘look after’ her are concealed. As intensive care units define themselves in relation to the criteria for admission and a potential for recovery, Dottie’s actions are increasingly threatening her potential for recovery and as a consequence the underpinnings of intensive care, even though she requires not only more treatment and observation than is available on the general ward, but she now requires more intensive observation than many other intensive care patients. The observation she requires is not related to her pathology directly, but her actions and, in turn, it was the consequences of her actions that proved troublesome for intensive care.

Within intensive care she became increasingly difficult to manage, as gleaned from the handover between the nurses in charge. Whilst Sally, the staff nurse referred to in the handover (Chapter Eight), ‘wasn’t afraid of Dottie’, many others were, on account of her self-extubation and decannulation (removal of tracheostomy tube). She received a new term of reference because of her action, one of the consultants referred to her as a ‘serial self-extubator’. But through this fear of caring for her, Dottie had breached the established order of intensive care; she was not simply a challenge to care for, but a challenge to the intensive care system itself. She was far too great a risk to remain ‘one of ours’ and as a consequence became ‘othered’. Through the excess work of and danger associated with reintubating, through the numerous staff who

requested not to work with her, and through the groans she elicited when her name was mentioned within the private spaces of intensive care, the difficulty intensive care had in her 'management' was emphasised. As a consequence her disposal was desired as a matter of urgency, such a disposal would meet the demands of a smooth running intensive care unit.

As has been demonstrated in relation to the construction of a critically ill body (Chapter Six), the body is processed, plugged in, ordered and rendered legible. Once rendered legible the body becomes treatable. Once treatable, the body becomes 'one of ours'; this idea of ownership comes through in relation to how nurses and doctors in intensive care refer to patients, as 'Dave's' patient' for example. In turn, this helps classify who is a legitimate patient and who is not, such as Roy (Chapter Seven) who is seen as a 'bed and breakfast' patient. Through the use of the term 'bed and breakfast' something is revealed about how intensive care regards such a patient. It is in part recognition that intensive care is not his proper place - his time within intensive care is limited, his ward bed is kept for him, and the nurses grumble about the fact that he is brought to intensive care at all. However, the grumbings are not so much about Roy as they are about the relationship and tensions between anaesthesia (within the recovery unit) and intensive care (through the nurse) and the tensions between the two spaces. Roy became the ground from which the disagreements over appropriateness for admission were fought and settled.

Intensive care has no toilets, shower or wash facilities for patients, all the patient has, with limited or no access to, is arranged around their bed, which they cannot leave. They have their space (as previously mentioned in Chapter Six), their place, the bed in which they are embedded. The space is not for the vocal and the mobile. Whilst Roy was kept in the intensive care unit overnight, it wasn't long before he was moved on, transferred back to wherever it was he came from, via the High Dependency Unit. For Roy, unlike Dottie, the process of 'othering' never really got under way, he was never seen as being in the right space in the first place, he was always other within intensive care. Dottie acted consistently with the accounts of her provided by her family, but within intensive care, this was problematic and gradually she was transformed from a legitimate intensive care patient to an 'other'. While she fitted the criteria of being an intensive care patient, it was decided that she would better fit an

intensive care unit elsewhere. Roy, on the other hand, was seen chatting to Albert and the two nurses and on the face of it could be seen to fit in within intensive care; he was able to joke with a group of four males. However, it was because of his reason for admission and that he could be equally well cared for elsewhere that he was not treated as a *bona fide* intensive care patient; intensive care was not the place for him to be. Of course the other is not as simple as presented, should Roy 'go off' as they term it in intensive care, referring to a rapid physiological deterioration, then he would be in the right place, but for the intensive care staff this would be unlikely. Perhaps, significantly, it is the route that Roy took in getting to intensive care, and the doctor who referred him over, that settled the question as to Roy's place. It was through an invocation of a genuine physiological issue that was translated by intensive care staff as something quite different that created the initial tension. The basic physiological monitoring was taken as being overlooked by the anaesthetist, and this above all else gave rise to his admission. That is, his presence had more to do with poor medical care on the part of the anaesthetist than it did with ensuring that Roy was in the most appropriate space, 'her' (the intensive care nurse's) bed space.

As with many post-operative patients who pre-operatively are deemed likely to require admission into 'Critical Care', they have had a junior doctor from the surgical team book a bed (as referred to in Chapter Six) and indicate the dependency level of the patient. The Critical Care staff can then 'judge' whether such an admission would be appropriate and can alter the anticipated dependency of the patient which in turn determines whether or not the patient is appropriate for 'Level 3' (intensive care) or 'Level 2' (high dependency care). As the anaesthetist emphasised a cardiovascular instability, he felt that intensive care would be appropriate and couched his words in order to legitimate an admission. Within the High Dependency Unit (HDU), the nurse sometimes assesses the patient when they enter the Recovery Unit, to see whether they feel the patient requires a HDU bed or should go to the ward. If they feel the admission is inappropriate they will refer the matter to the nurse in charge who may well take the matter up with either the anaesthetist or with the intensive care consultant in which case admission or non-admission will be settled. Intensive care patients, or at least those destined for intensive care are transferred by the anaesthetist and rarely visited by the intensive care nurse or doctor, if they are seen within the Recovery Unit it is by invitation of the anaesthetist or surgeon. Otherwise, the patient

will be admitted and the anaesthetist is generally taken on their word. However, when Roy arrived and processed (embedded) into intensive care, the nurse acted as though she had been duped by the anaesthetist and voiced her frustrations to the intensivist, who took no further action, or at least deferred any action. So, from the outset, Roy was 'othered'. After a sleep, an uneventful extubation and a spot of breakfast, he could go back to a more natural space for the 'clearly too well to be here' patient, who was seen to have gained access through 'the back door'.

For Bauman (1994), bureaucracy (and business) is bound in with the achievement of being moral and to be moral is to extricate affect; for the most part, those emotional elements which are required as part of the functioning of organisations: loyalty to the company and loyalty to fellow members. Through this thesis and much of the discussion, the idea of the organisation and its members has been thread through and invoked as part of intensive care and other, from the staff to the appropriate and non-appropriate patient. The weight of management to enforce change through a particular vision of health policy strips those aspects of particularly the High Dependency Unit to an adjunct, an 'other place' which has had its own management removed and distilled into the greater whole of Critical Care. Any reference to High Dependency or Intensive Care became a form of resistance and was quashed by those who held managerial authority; the words of its staff are controlled by their managers. The idea of intensive care had to be removed from everyday talk to enable a new discourse of 'Critical Care' and patient dependency. Critical care patients are treated according to dependency, not in a particular space with the most appropriate resources as 'the resources should follow the patients' and to some extent this holds because the team has no choice but to accept this discourse, even though the idea of intensive care 'slips' out on occasion. Yet, the lure of intensive care as a concept continues, effaced by government and the managerial staff. It lives on in some hospitals and it has a popular and powerful imagery associated with it, as witnessed from the newspaper headlines (Chapter Three). Other hospital staff only recognises it as intensive care and patients and families understand what it means and so it is partially resurrected by staff as it is a useful distinction between the High Dependency side of Critical Care and the Intensive Care side. As a concept it flits between spaces of existence and non-existence, being at the same time part of the present and reminiscent of the past.

The previous HDU is now run centrally; the nursing staff who enable the place to exist are segregated into one of eight teams out a total of approximately 150 qualified nurses within intensive care. Significantly what Comprehensive Critical Care (DoH, 2000) enabled is the allocation of more patients to fewer nurses⁸, one nurse for two patients within high dependency as opposed to one nurse to one patient within intensive care, allowing a nurse to be allocated to more than one patient within intensive care as opposed to the single patient. The teams rotate monthly so that everybody has a period on each of the three units, but for the most part, the High Dependency Unit is where nobody wishes to be allocated, it has become the poor relation within intensive care where those patients that have been othered can rest until a more suitable place can be found for them.

Returning to the example of the intensivist at the door who refused the admission of a neurosurgical patient (Chapter Six), some of these practices can be better illustrated. Rather than outright disposal, the attempted admission was referred to the operating theatre or, as later seen, deferred entry to intensive care. The patient and entourage were forced out of the intensive care corridor and back toward the operating theatre at the opposite end. The admission could be seen as breaking the rules; access was being sought through the 'back door', at least metaphorically. Another consultant may have accepted the admission as the patient was mechanically ventilated and, as such, appropriate. However, at this point in time it was *his* ICU and this was displayed by him to those witnesses around the bed. It was not only his talk, 'and where do you think you're going', but that he occupied a position between the front of the stretcher at the patient's feet and in the doorway of intensive care. Rather than a performance of persuasion, he was performing authority of this space. It was being performed as his intensive care and if the transferring team did not inform him of the admission then they could not realistically expect to gain access to his space. Once the repair work had been performed by the neurosurgeon, the consultant granted access, and only once he had granted access, even if provisionally, could the surgery be performed. When looking back at the relations between anaesthesia and surgery within a particular context, as laid out in Chapter Three, the significance of this dual

⁸ Nurses are far and away the most expensive technology within intensive care (Hinds & Watson, 1996).

trained anaesthetist/intensivist makes itself clear; he can now move into the world of the surgeon, unlike that of Dr. Lukes at the turn of the twentieth century.

What this section of the discussion has done is to draw upon the issue of disposal and the ways that disposal is made operational within intensive care. It has explored some of the conditions for such a disposal to be made legitimate and how they are carried out, while also demonstrating the camaraderie among the staff of intensive care through which alterity is partially accomplished. But intensive care as a concept has been disposed of. As alluded to in relation to the defiling and civilising aspects of the mouth (Chapter Seven and Eight) things out of the correct spaces are refigured as polluting, of dirt and dangerous (Douglas, 2002). Now intensive care has been reworked as polluted, and disposed of as have those High Dependency Unit nurses who refused to be a part of this new system, they were 'let go', disposed of as the new system has to be embraced wholeheartedly. Similarly the ethics submissions were the wrong things in the wrong spaces, polluted and disposed of, the patients, the histories in some way through the thesis have been a subject of disposal, materials in the wrong spaces. But conversely, through the materials and their invocation, the production of culture is made visible.

There is an antagonism between developing an ethnography that engages with its own theoretical position and securing a successful ethical review. Bureaucratic and accounting structures, such as those associated with ethical review, can be read as external rituals of verification (Power, 1994; 1999; Strathern, 2000b) that do not tie in with the ethical position that is central to the ethnography itself. These external systems of verification examine the visible attributes of the research in a general sense. When the internal assumptions of the research are laid bare, or taken out of the black box (Latour, 1987), approval of such research becomes problematic as the 'holding' features are challenged. As with the Trickster myth, in which Trickster carries the body's organs external to the private internal spaces of the body, the body of this research was carried outside of the black box of its internal workings and assumptions, and displayed on the outside. As a result, the research did not 'look like any kind of ethnography' the panel member had seen before. This is, in part, because many aspects of ethnography, such as its theoretical position, are often concealed but this research displayed its positions on the outside, which is one aspect that made the

research a particular danger for the panel. So, to some extent, the research made visible those things that should remain hidden from verificatory structures such as the review panel (which is what happened in the first, unproblematic application) including the assumptions it rests upon. As a consequence the research was deferred across numerous panels, but never quite disposed of.

Through disposal, of bodies, persons, beliefs and the deferral of patients or research, the effects of organising principles such as policy, accountability and bureaucracy are witnessed through their particular effects. Within such forms of organisation there is no place for an alternate position or viewpoint, through engagement such as a dismissal of the alternate, the position or viewpoint of the organisation becomes visible. The dominant and dominating way of seeing holds and it is the means through which all potentialities are interpreted and, as a consequence, judged. Disposal and deferral are a consequence of such a judgement and through such actions the judgement and processing of judging are witnessed. The witnessing of a given cultural performance, such as through this ethnography, is itself mediated through a particular way of seeing the world, the arguments presented as well as the ethnographic (re)presentation can be traced back to some extent to the position of the author, made visible through a certain discourse which give clues to and make visible a certain ontological position, or 'domain assumption' in Gouldner's (1971) terms.

As the field, and its organising principles (or moral order), can be made visible through its accomplishments, so too can the research itself be made visible through its representation of the field. However, these issues of argumentation, editing of (re)presentations are not always known until after it has been written. It becomes an issue of authorial intention, as Derrida (1976) put it. So a particular ontological position alters the materials invoked and its (re)presentation, it is involved in concealing and revealing, of being a part of and distancing, of disposal, deferral and inclusion, of similarity and difference. This is part of a paradox of attempting to write ethnography in a way that is mindful of the problems of legitimation and representation, the focus shifts to that ontological position as I will argue in the subsequent section.

It is exactly these issues as a cultural effect that have been invoked in order to demonstrate the partial and contingent means through which policy is invoked, the means through which regulations and bureaucracy shape the ways in which things are seen and in turn enable a judgement to be made. But again these are also issues associated with the research endeavour itself, as the field can be critiqued according to problems of legitimation and representation, so can this ethnographic representation of a given field. The epistemological position to some extent drives the research in a certain direction, much as the cultural reality of intensive care or ethical review is driven from a certain perspective. However the intention with the research is to make this ontological and epistemological position explicit. The problem of course is that through this revealing of the ethnography, other aspects of ethics and intensive care are inadvertently concealed, which is why the partial connections between materials and performances within the field become so important. They aim to tie together the connections beyond the epistemological whilst recognising that the performance, practice and culture of intensive care have their own ontological and epistemological grounding. These issues have been introduced in specific reference to intensive care and the normalising and normative judgements that are made visible through the embodiment of particular policies, practices and performances. This is what has been demonstrated in relation to materials and disposal. For the next section I will demonstrate how these materials are invoked, their particular accomplishments and in turn the means through which a given cultural site can be read and understood through such materials.

Drawing up an Extension.

Hold on, you have to slow down. You're losing it, you have to take a breath. Listen to yourself. You're connecting a computer bug I had, a computer bug you might have had, and some religious hogwash. If you want to find the number two sixteen in the world, you'll be able to pull it out of anywhere. Two hundred and sixteen steps from your street corner to your front door. Two hundred and sixteen seconds you spend riding on the elevator. When your mind becomes obsessed with anything, it will filter everything else out and find examples of that thing everywhere. Three hundred and twenty, four hundred and fifty, twenty-three. Whatever! You've chosen two sixteen and you'll find it everywhere in nature. But Max, as soon as you discard scientific rigor, you are no longer a mathematician. You become a numerologist. What you need to do is take a break from your research. You need it. You deserve it. Here's a hundred dollars, I want you to take it. If, you won't take it, borrow it. Either way, take a break. Spend it however you like as long as it falls in the category of vacation. Real world stuff, okay. No math.

(Extract of Screen Play from the film *Pi* by Darren Aranofsky:
<http://www.imsdb.com/scripts/Pi.html> [accessed 11/12/07]).

As the preceding extract from the film *Pi* demonstrates, once a certain thing is focussed upon intently, it appears wherever one looks. That which is looked upon and taken to hold (Latour, 1991), in turn, becomes almost the only way that a given situation can be perceived. In some respects the focus becomes the world and as Max's supervisor suggests, a break from this particular focus is required. It is precisely this idea of focus, as a particular performance, context or idea that brings into play the significance of an ontological position and its relations to the epistemological. It is precisely this idea of focus that distinguishes self from other, the ethical committee member from the researcher, the patient from the staff, the nurse from the doctor, the history from the organisation. They are all concerned with a position, a way of seeing, and any position which does not follow this particular format is by its non-association, 'other'. This othering is not just about physical disposal, such as in the case of Dottie, but about a non-alignment or a progressive recognition of a non-alignment in the first instance, or as a point of perspective. Tied in with multiple discursive formations (Foucault, 1972) that align or do not align, the moves made by the practitioners, the patients, the ethics committee are similarly to do with a non-alignment, which legitimates a disposal or deferral and in Foucault's terms can be viewed as a system of dispersion (1972). Within this there is little leeway for an alternate position or perspective, particularly when it refers to accountability and the implementation of policy. There is little space or desire for an alternate perspective; an alternate perspective becomes dangerous because it challenges the tacit and the taken for granted and if engaged with as opposed to deferred or disposed, it forces an engagement with the alternate.

Within these discursive formations the actions are consistent and as a consequence legitimate. As alluded to in the previous section of this chapter, bureaucracy can be seen as a potent device which regulates and controls the social within modernity. As there are limitations to the expression of affect, which results in the expression of loyalty to both the organisation and to colleagues, there are limitations of perspective. Through bureaucracy there can be only one legitimate voice; that of the institution, or the organisation. Multiple accounts, narratives, perspectives (Lyotard, 1986) become null and void, competing perspectives cannot be tolerated; the univocal becomes a space of security, of safety. As a consequence, the organisation itself becomes a technology of deferral, of disposal, of dispersion, for the most part as a means through

which the security of the institution can be assured. The regulatory functions of bureaucracy in turn become the world, the legitimate reality, through which the technologies of dispersion can operate. But of course, Dottie, or the research project does not disappear, it is not killed or incinerated, it is transferred from one place to another, as Dottie was transferred, as the errant admission was pushed back to the operating theatre, or as in the case of this ethnography, the research was deferred. Throughout the thesis, thick descriptions of deferral, disposal and dispersal have been presented from which an ontology of modernity has arisen as a means through which the social is read, reproduced and made sense of within intensive care.

Challenges to a particular perspective, such as the nurse suggesting the consultant 'maximised trauma' as opposed to the consultant's assertion that he 'minimised risk', are dressed in humour as part of a performance of Ward Round. Even though it is a particularly cutting critique of the consultant's action, the nurse's resistance is made marginal to the real and present threat to intensive care as a bureaucratic system presented by Dottie. The nurse who questioned the appropriateness of Roy from the recovery ward, a questioning that the consultant 'ordinarily' agrees with within the confines of the coffee room (Goffman, 1959), is down played within the context of the ward round. Thereby suggesting a legitimate site of resistance, but that site is not the bed side, so the concerns can be cooled out (Goffman, 1952), put to one side, dispersed, at least for this point in time and within this space. The allegiance could be seen to have switched from intensive care nurse and intensive care doctor to the intensive care doctor and anaesthetist. There is an appropriate time and space of resistance that is not the ward round and not the bed side. This suggests that it is down to the spaces in which things are spoken and the timing of its invocation which is significant to the act of resistance and not necessarily down to professional allegiances (doctor to doctor) or spatial allegiances (intensive care staff to intensive care staff). In many ways the coffee room, which has not been a prominent feature of the ethnography, and private spaces such as the lavatory become the private space of resistance to a particular way of seeing and performing intensive care.

In order to tap into these ideas of dispersion and deferral within the ethnography, Strathern's (2004) notion of amplitude was adopted, which enabled particular understandings. The amplitude has been increased and decreased at differing points,

providing fine detail in some areas, with others more airbrushed, as is necessary through the contingent of ethnography within a single site. As the research was based upon a single site, the focus has been upon the multitude of ways of seeing within intensive care, the performances of those within intensive care, and the representations of those about intensive care from the popular representations to a certain historical representation. The intention has been to reproduce an idea of intensive care that touches upon multiple voices, but highlighting how these multiple voices are constrained to see and speak about intensive care in a particular way. Through the bureaucratic ontology, there can be only one way of seeing intensive care from the position of the service providers. However, the attitudes of others toward intensive care enable a disparate perspective beyond that which is regulated by policy and the organisation. Through popular representations and the performances of the patients themselves a demonstration of the 'holding' power of the bureaucratic technology of conformity and the consequences of challenging it are revealed. An 'other' perspective becomes so much more important; a perspective from which the accomplishments of intensive care can be witnessed. But over time the dominant 'holding' perspective becomes the only way of perceiving the space, as the other becomes 'one of us', the perspective is shared and becomes the lived reality over all others. Intensive care as a particular place, including the rules, systems and technologies that constitute it, are part of a way of seeing, being and doing, as well as a physical space. However, what has been demonstrated is intensive care as a heterotopia, a space of alterity, multiple and partial readings.

Through the presentation of micro-interactions (Collins, 1994) and performances within intensive care, the accomplishments of the culture have been made visible on a small and localised scale. Through the histories of intensive care both in secondary form and developed through the ethnography, the scale of the research increases and, again, the relations are made visible at a different point of amplitude (Strathern, 2004). Broader concerns of the media and policy have also been presented and relayed back to the other layers of analysis, seen through the interactions within the field as a particular effect or accomplishment. The 'levels' of analysis have played back and forth across 'levels' of amplitude, tracing relations between spaces, from the field, from the popular imagination, from forms of history, and in so doing, relations can be made through the materials that are invoked. The performances of patients and

staff have been seen as a particular way of invoking materials from other spaces, such as ethics, of discounting materials of others and of disposal of materials. What has been attempted to some extent is an assemblage (DeLanda, 2006) of intensive care in relation to materials and performance. This in turn has highlighted the holding power of modernity through the ways in which intensive care is organised, practiced and laid out as a particular space and has particular effects on its staff, patients, and the numerous sorts of 'visitors' to intensive care.

Intensive care has been presented as a particular space, as a technology, a mode of organising and organisation. It is a site characterised by invasive medical technologies, the medical machines and those people who serve the machines. Zussman (1994) has suggested the patient 'vanishes' and then 'reappears', but what has been suggested here is the centrality of the body to intensive care, even if it is rendered less visible at times; the organisation is centred around the bed spaces which are centred around a bed which house and display a critically ill body. Within an embodied sociology, for the patient to disappear, the body should be disappearing with it, yet the body and the patient remain, accomplishing the mundane social at different points of their career (Goffman, 1961) as a critically ill patient.

However, the technologies of intensive care, such as the chart, the computer, the monitor, the ventilator, the syringe driver, the sinks, the bins and so on, have the effect of diverting the gaze, the centre of attention, the focus of health care staff and of family members. The body is turned away from and the technologies, objects and materials are turned towards, which is bound up with the ways in which technologies shift focus and attention from the body to the monitor. An alarm sounds and the attention shifts towards it, irrespective of whether a staff member or a relative. The alarm in this case works, it receives the attention it is presumably designed to provoke and in a way is a small example of how technologies call upon the gaze. What is significant is that this looking upon the technology focuses the attention, to the exclusion of other things, such as the body, the suffering individual. This in turn becomes the only way of looking, of perceiving, of interpreting, and as argued previously it renders the body legible in a specific way. This legibility, unlike a representation, is open to renegotiation; it is contingent, as referred to in the previous section of this Discussion. The body becomes visible in relation to its intersection

with sustaining technologies and the technologies transform the way in which the body can be seen. The physical technology of intensive care, like the organisational technology of bureaucracy becomes the only way to see, the legitimate and legitimating way of seeing being and doing. These technologies as Luhmann (1990) phrased it can be conceived of:

‘as a simplification within a causal context, a simplification that has its own consequences’.
(Luhmann, 1990; p.223)

Within this thesis, these simplifications are part and parcel of what the technology is about and that is reducing a given perspective to a singular and localised view. This has emerged throughout the thesis as means through which a certain perspective is held and how differing materials are invoked as a performance of legitimacy. However, the flip side is that the perspective is restricted to that amenable through the technology, an indexicality in one sense whereby a perspective is reduced in order to comply with the contingencies of a given technology or format (Garfinkel, 1967). Through technology the world of ‘mess’ (Law, 2001) is reduced to something tangible, something smaller and reduced, something that can be engaged with, but in doing so the world of mess is filtered out of the equation. As academic study branched out into smaller ‘disciplines’, following the enlightenment, more specialised forms of knowledge production took place. The technology of the indexical has been perceived as important in the development of the sciences, being able to focus on say physics without having to worry so much about theology, or biology, or chemistry. However, this reductionism as bureaucracy or simply engaging with technology has important consequences on how the social world is related to, ordered, performed and reproduced. Within such a light, the space of intensive care, of ethical committees and bureaucratic systems can be seen as technologies of control and manipulation. But these technologies can only control and manipulate because they are believed in; they hold because they hold, in Latour’s (1991) terms. And because they hold they, in turn, become the only way that the world can legitimately be witnessed, within the culture’s own recursive logic (Giddens, 1987).

This thesis adds up to an exploration of legitimacy, of ascribing legitimacy and the performance of legitimacy and the way that certain interpretations hold as fact.

'But, of course, adding is accumulative process, an ongoing process into infinity that does not necessarily need an equals sign.'

(Hetherington, 1998, p. 157).

To conclude is to suggest that the story is over, the story of intensive care whilst in some respects may be regarded as over with the advent of critical care, but it survives through. In short this chapter aimed to add without the equals signs (Hetherington, 1998) and recognise that there is no final unitary issue, just interpretations and the writing of ethnography, which is of a particular cultural scene that has its own finitude.

Through 'drawing up' intensive care, the means through which it constructs, deconstructs and reconstructs itself as a specific site of performance and of invocation can be seen as a particular trope of the performance of modernity. It is through intensive care as a technology of extremes, of life and death, speech and silence, sacred and profane, that the stakes become that much more powerful; the technology has to be relied upon; there has to be a particular means of perceiving in order to upkeep its efficiency and legitimacy. As such, it can be seen as an alter to modernity and in this way it deals with the ultimate stake of life and death, it contains surveillance technologies that 'read' the body, predictions are made about the body's prognosis and the body is controlled by those technologies. However, what this thesis has demonstrated the intended and unintended consequences of intensive care as a technology, the organisation (the moral order) of intensive care as a technology of control and the specific monitoring support technologies as another system of control. Through the technologies that constitute intensive care, aspects of social relations which ordinarily remain less visible resurface as crucial within such a space, this in turn has repercussions on how the 'social' is understood within everyday social life which is (in part) why the intensive care unit is such a critical site.

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Appendix One.

Research Protocol.

1 Background & Introduction.

1.1 Background.

This research forms part of an Economic & Social Research Council (ESRC) funded research project which aims to trace the organisation and practice of critical care and its consequences on patients and family members. This follows a pilot study which investigated verbal and non-verbal interaction within intensive care unit (ICU) between staff members, family members and patients'. This study, which received ethical approval from the Local Research Ethics Committee (LREC) in July 2002, is now being extended to elicit the personal accounts of patient and family members' following discharge from intensive care. The Intensive Care Unit and High Dependency Unit (HDU – an area of the hospital that caters for patients that require more intensive monitoring than is generally available throughout the general hospital ward, but do not require the specialist technology and expertise available in the intensive care unit) have been subject to transformation in their organisation and practice since the pilot investigation as a result of policy changes (Department of Health, 2000). The two areas have merged to create a 'critical care unit without walls', which treats patients according to levels of dependence within the same unit as opposed to the discharging of patients when they recover from the acute and life-threatening stage of their illness. In effect, patients are located according to dependency. This has given rise to a new way of working within critical care which will impact upon how treatment is experienced by both patients and family members alike in addition to how critical care practitioners view the delivery of care. As such the investigation aims to map the organisation and practice of intensive care and develop understandings of how critical care impacts on patients and family members following discharge from hospital.

1.2 Introduction.

On average, 1-2 % of the hospital's total number of beds will be ICU beds (Bennett & Bion, 1999). In *****, approximately 2,300 patients are admitted to intensive care every year. Patients present with a potentially recoverable yet serious condition (Spiby, 1989), however, the national mortality rate associated with ICU is around 31% in referral centres (MacDonnell et al, 1996), with a further 27% of patients dying within one year of admission to ICU (Goldhill & Sumner, 1998). There is a significant physical and psychological morbidity associated with ICU, including: post traumatic stress disorder, acute stress disorder, depression (Perrins et al., 1998; Bennum, 1999), insomnia, sexual problems, limited mobility, breathing problems, swallowing problems, chronic itching (Waldmann, 1998) and relationship problems (Griffiths & Jones, 1999). The Audit Commission (1999) and the Department of Health (2000) have stated that some form of follow-up (out patient) services should be in place in order to tackle some of these issues; however their provision has not been widespread through Wales. Furthermore, intensive care has had a radical revision of the way its services are provided through the recent White Paper (DoH, 2000) involving an amalgamation of High Dependency and Intensive Care services,

categorising patients according to dependency within a large combined critical care unit. The effects of such reorganisation of service provision on patients, families and health care staff are unknown.

Given the problems that patients experience after discharge from ICU (or level 3 critical care as it has become known) there is an urgent need to better understand the social and personal issues affecting patients treated in critical care. Specifically, there is little research on the longer term effects of what it is about 'ICU' that impacts patients' and families' personal and social lives. Research to date only takes into account patients perspectives on or just after their discharge from the ICU (Perrins et al, 1998; Russell, 1999). There are no longitudinal studies of patients discharged from ICU and none that examine organisational practice in relation to patient experience. Social studies of ICU indicate that the social organisation of intensive care may have a major impact on the experiences of patients and their families (e.g. Seymour, 2001), and may even have longer term consequences for patients and their families, in terms of their ability to readjust and recover their normal relationships and lifestyle. No previous studies have attempted to put these two perspectives - those of patients' accounts after discharge from intensive care, together with observations and detailed descriptions of the social organisation of treatment and care in the ICU. As such this timely investigation not only seeks to explore accounts of those who have passed through the critical care area and how they reconcile that experience within their daily life, but the impact of '*Comprehensive Critical Care*' (DoH, 2000) on those involved in its everyday practice. This study offers a unique opportunity to explore both the longer-term effects of critical care on patient's personal and social lives, and the relationship between people's accounts of their experiences of intensive care therapy and observations of the social organisation of critical care.

2 Study Aim & Objectives.

2.1 Aim.

To explore the personal and social (if unintended) consequences of the organisation and delivery of intensive care on patients and their families from the perspectives of ICU staff, patients and close family members.

2.2 Objectives.

Objective 1: To analyse the organisation and practice of critical care.

Objective 2: To explore patient's perceptions of critical illness following a period of admission to a critical care area.

2.3 Secondary Research Question & Objectives.

Is there a relationship between the ways in which intensive care treatment is delivered and organised and patients' and their families' accounts of their experiences of the intensive care unit?

Objectives of the research:

- Create detailed descriptions of how intensive care is delivered and organised.
- Explore the social significance of these methods of delivery and organisation for patients and their families.
- Discuss findings with intensive care staff and other interested organisations, such as Intensive Care National Audit and Research Centre (ICNARC) and British Association of Critical Care Nurses (BACNN) to develop

understandings of how the delivery of intensive care treatment and the organisation of intensive care can support patients and their family's personal and social needs.

- In collaboration with staff and the aforementioned organisations contribute to understandings about the need for follow-up services for some survivors of intensive care.

3 Study design.

3.1 Methods.

The main thrust of this investigation is on the experience of intensive care patients and family members following discharge, enabling an investigation of the impact of critical illness on individual patients, and how that experience is mediated by family members and professional caregivers. A particular concern is to illuminate the experience of patients and family members themselves, contrasted against what has been observed as well as the accounts of health care professionals. This will offer a thorough contextual grounding of the research through the combination of more than one research method. Taking the approach of contextualising patients experiences and the consequences of treatment, the proposed methodology closely follows two earlier PhD studies in highly sensitive acute medical settings: one of older people admitted as emergencies to an acute medical unit in a prestigious UK teaching hospital (Latimer, 1994; 2000) the other of men admitted to an Australian burns unit with third degree burn injuries (Rudge, 1997).

3.2 Study design.

Stage 1 Objective: To map all aspects of the organisation and delivery of critical care clinical process.

Method: Observation of all aspects of clinical process and the organisation of care.

Stage 2 Objective: To explore patient and family members accounts of their experiences of critical care.

Method: Interviews with patients who survive ICU and their family members.

a) Towards the end of their hospital stay and once their condition has stabilised, patients [n=15-20] who have survived ICU treatment will be interviewed together with close family members to explore views of their experiences of ICU and elicit accounts regarding the patients' recovery and current condition. This will be a short interview aiming to develop a brief overview of experience and establish relationships prior to follow-up interviews.

b) Follow-up interviews with patients and close family members to explore the longer term consequences of their experiences of ICU. These will be conducted at a location convenient for the participants at 2, 6 and 18 months after leaving the ICU. This will contextualise the accounts of patients and family members' experiences of ICU within their own lives, enabling an examination of the significance of treatment within the ICU in the longer term.

Stage 3 Objective: To understanding the meanings that specific aspects of clinical process and the organisation care have from the perspectives of practitioners.

Method: Interviews with a representative sample of ITU staff directly involved in the organisation and delivery of ITU treatment and care to patients – doctors, nurses, managers.

3.3 Interview & Observation.

All aspects of ICU organisation and policy with regard to patient assessment, treatment and care will be mapped and observed. Interviews will be held with health care professionals, managers and policy makers (where appropriate), in order to develop an understanding of the cultural milieu of critical care from the perspectives of those involved in it. In addition conversations, such as medical ‘ward rounds’ and ‘handovers’ will be audio-tape recorded with the knowledge and consent of those involved, this enables a view of how the ICU is constructed and experienced discursively (through discourse) by critical care staff.

Interviews will be conducted with patients, families and health care staff at various locations, questions will be based on individual experiences. It is anticipated that participants will discuss aspects of their experience which may not have been previously considered by the research team, however, the key research questions posed to patients will be:

- Tell me a little about your experience of the intensive care unit.
- Do you recall your experience of the intensive care unit.
- What to you is the most significant aspect of your experience of the ICU.
- Do you remember entering the intensive care unit.
- How did you feel about transferring from the intensive care unit to the ward.
- Were there particularly positive aspects of the experience which spring to mind.
- Do you recall the presence of your family.
- Were there any procedures performed within the intensive care unit which remain particularly prominent in your memory.
- How do you feel now about your experience of intensive care having left the intensive care unit.
- How do your family feel about your treatment within the ICU.
- What has your family told you about your treatment within the ICU.

Those interviews undertaken at home will follow a different course and will be related to the previous interviews:

- What is the most significant experience in your life?
- How does your experience of being in intensive care compare to that?
- You told me that (a particular experience elicited from previous interview such as insomnia) stood out in your mind, how do you feel about that now?
- Do you get a chance to speak to your family about your experience of being in intensive care?
- How does your family relate to you now that you have returned home?
- Are there things that you cannot do now that you could have done before your admission to intensive care (aside from, for example, physical limitations).
- Do you feel that the experience has changed you as a person?

Family members will be asked similar questions but related to their experience of visiting the patient, and their relations with them on their return home. In addition, observation of health care practices such as ward round and handover will take place and notes will be made on-site providing a context from which interview material relating to the experience of critical care can be judged. However, it should be noted that this is a 'general' observation which is not focussed on the patient or their family but on the organisation and practice of critical care. The observation will focus on the individual layout of intensive care, the routines (such as handover and ward rounds) and will be performed in individual blocks up to 2 hours per day at different periods of the day over 2 two month periods. Should any incident occur which challenges the patient's (or families') right to privacy, dignity or safety, the observation will be terminated.

3.4 Inclusion Criteria

Participants must fulfil the following criteria to be included within the study:

- Current hospitalisation within critical care at the time of the investigation.
- Having received treatment within critical care.
- Admission to critical care anticipated greater than 72 hours. Note that only those patients admitted for greater than 72 hours will be enrolled as these are the patients most likely to develop deleterious symptoms attributable to intensive care treatment (Jones et al., 2001).
- Considered suitable for inclusion by nursing and medical staff.
- The participant must consent for inclusion.
- Ability to speak English. Only participants whose command of English is sufficient to participate in an interview will be included in the study due to limited facilities for translation.

3.5 Exclusion Criteria and Withdrawal of Participants.

Participants cannot take part, or be withdrawn from the study if:

- They have been admitted following a severe head injury.
- They are under 18 years of age.
- They experience significant emotional distress as a result of treatment in the ICU.
- Any of the inclusion criteria are absent.

4 Analysis & Presentation.

4.1 Analysis.

The methodological approaches to be used in this qualitative research are Code and Retrieve - a method of identifying themes within transcribed interviews through their constant reading and re-reading, and through the use of Computer Assisted Qualitative Data Analysis Software (CAQDAS), which aids in the identification of recurrent themes. Additionally, constant comparative methods (Silverman, 2001) will be used; internal validity shall be achieved through continued feedback with research participants. Cross checks on interpretation will be made:

- a) Across cases, that is between individual patients and family interpretations of experience.

- b) From different registers, for example cross checking observational data from field notes with interview accounts, unit policy documents with practices.
- c) Over time, patients' accounts will be cross checked against themselves at different periods following discharge from intensive care.

As well as cross-checking interpretation across different patients' treatment and experiences, and to wider views of ICU organisation and care, the analysis will be further validated by feeding preliminary findings back to patients, family members and staff members to check for saliency and relevance (Silverman, 1993). Findings, together with

Material deriving from the feedback of patients, their families and staff members will be used to identify methods for meeting the particular needs of ICU patients in terms of support during and after ICU care.

4.2 Presentation.

Findings will help inform policy debates through the Intensive Care National Audit and Research Centre (ICNARC). The completed research will be written up as part of a thesis for the degree of Doctor of Philosophy and will be available from the British Library and Cardiff University library. It has been agreed that results will be published in the Journal Nursing in Critical Care supported by the British Association of Critical Care Nurses. Further publication in academic and professional health care journals will allow dissemination of the research findings. Presentations have been made to academic and professional audiences (e.g. White & Latimer, 2003a, and b) and will continue to be made to intensive care staff through the bi-monthly research group meetings from which findings can be disseminated locally.

5 Ethical Considerations.

5.1 Access and Ethical Approval.

Experience of interviewing people in critical care has been developed from the pilot study. The study will be conducted in accordance with British Sociological Association and Royal College of Nursing guidelines for social science and health care research, advice will be sought from senior academics and staff members where appropriate. Having been approved by the NHS trust (03/aic/1854), the Chief Consultant (on-site principal investigator) in addition to Cardiff University (SPON CU 045), the investigation will receive ethical approval from South East Wales LREC (05/wse03/2). When interviews are performed at the participants' home, a chaperone in the form of relative or carer will be present during the interview.

5.2 Informed Consent.

Fully Informed Consent will be sought from each subject involved within the study. The aims of the investigation and the participant's role within it will be explained fully by the on-site researcher. Staff members will be approached in the first instance in order to ensure that it would be appropriate to speak to family members who will be informed of the nature of the investigation and consent will be sought. At this stage if family members believe that they would not wish to participate, they and the patient will take no further part in the investigation.

5.3 Process Consent.

Both the formal informed consent and the proxy consent process will be processual, that is, with each encounter, verbal assurance will be sought in order to elaborate that their consent to perform, or continue with the study still stands, which will be an integral part of the research process. This will allow the participants to voice their opinion at any time, and further giving credence to their permission for the research to be performed.

5.4 Confidentiality.

All material containing personal details will be anonymised. The only information which can be identifiable (but with access restricted to the on-site researcher alone) will be the contact details of participants for follow up interviews to be performed. These names and addresses will be kept in a separate locked cabinet from the anonymised transcripts of data. All original notes and recordings will be destroyed within 1 month of transcription.

5.5 Data Protection.

All information collated during the process of the research will be treated in accordance with the data protection act. Information will be processed on a personal computer which has no internet access, and will be stored on a floppy disk which will itself be stored in a locked, secure filing system; this will also apply to hard copies of the material. Access to identifiable research materials will be restricted to the on-site researcher, who respects the primacy of the material and under no circumstances, except that decreed by law, will the material be available to any other party. Further, on completion of the study is complete any identifiable information will be destroyed. Analysis of identifiable data will be conducted by the on-site researcher only. Cross checking of data will be performed with academic and professional colleagues only when the material has been anonymised. The analysis itself will take part in the researcher's office (based in the University).

5.6 Summary of Ethical Issues.

As all consent for this research will be fully informed, and as the research has no clinical impact, the ethical issues are minimal. Safeguards have been made in the shape of the fully informed consent process. Whilst the organisation and practice of critical care will be mapped and observed in order to create a comprehensive picture of the practices of a specific critical care area, some aspects of patient care may be observed. However, the focus is on the research site not the individual patient, family members or health care staff. Should any aspect of personal care have been documented its inclusion will be dependent upon the individuals fully informed retrospective consent. Confidentiality will be maintained throughout the research through the use of pseudonyms which will achieve anonymity for the participants. Additionally, all data retrieved will comply with the Data Protection Act of 1998. Participants will be able to discontinue their participation at any time. This research will have no bearing on their clinical treatment.

6 Protection of Subjects and Timetable.

6.1 Protection of Subjects.

Due to the sensitive nature of the research, medical, psychological and counselling staff have been made aware of the project. Whilst they are unable to take referrals for

patients or family members that exhibit emotional problems as a result of their treatment, or through the research, they believe that those concerned should contact their own General Practitioner who will have access to services that best meet their need. The on-site researcher has a background in intensive care nursing, and therefore has both professional and legal obligations to maintain confidentiality, acting in the patients best interests, and to recognise professional limitations, whilst the on-site principal investigator is the Chief Consultant for Critical Care Services. The research participants as part of the investigation will be encouraged to inform the investigator should they experience significant emotional distress, at which point they can be referred, and take no further part in the study. In this way, it is felt that some degree of protection, and in some circumstances treatment, is conferred upon the participants for any, albeit unlikely, untoward effects of this research.

6.2 Timetable.

It is anticipated that field work and interviews will commence for the first two month block in March, 2005 and continue for a further block in October 2005. Interviews with key informants will be undertaken at their convenience at any time during the period of fieldwork. Analysis of the data will commence with the first period of fieldwork, continuing with the write up of the thesis throughout August and Submission in January 2006. Further written reports will be made to the relevant professional and academic journals during the latter stages of the research.

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Appendix Two.

Full Patient Information Sheet.

1. Invitation.

Whilst you were unconscious, you were enrolled in a study which aims to examine the experience of patients like yourself who have needed treatment in a critical care unit. You are invited to continue taking part, but before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully and discuss it with others if you wish. Ask the researcher, Paul White, if there is anything that is not clear or if you would like more information. Please take time to discuss whether or not you wish to take part.

This leaflet will highlight:

- ❖ Why the study is being done.
- ❖ What has happened so far.
- ❖ What will happen if you decide to take part.
- ❖ What will happen if you decide not to take part.
- ❖ The possible risks, benefits and discomforts of taking part.

2. What is the purpose of the study?

This study follows an earlier investigation that aimed to find out how doctors, nurses and family members communicated with patients who were critically ill. This study looks more at the experiences of patients such as yourself (and your relatives), who have been through critical care and how it is remembered once you return home. Nobody really knows how patients and relatives get on with their lives once they return home, so the investigators think it would be good to find out how you feel about your experience of being very ill once you return home. This may help future patients and families who are in a position similar to the one you have been in. It is also an area of study that has not been investigated previously and will benefit future patients by making the medical and nursing staff more aware of your needs.

As well as this, the way that the critical care areas (once known as Intensive Care Units and High Dependency Units) are run is very different now to say 2 or 3 years

ago. This makes it very important to understand how this has affected health care staff, who will in turn influence how you may have experienced your stay in critical care. Sometimes health care staff do not realise how much what they do around your bed space can effect you, so they will be interviewed too. The research will be conducted over 18 months with patients and relatives offering a little of their time at 3, 6, 12, and 18 months after they have left critical care.

3. Why have I been chosen?

Your family have already agreed to take part in this investigation because how they feel about critical care will have some effect on you. You have been chosen to take part in this research because you have recent experience of critical care. As such, it is felt that given this experience you have a good contribution to make about how people feel having been involved in it. Around 15 to 20 patients will be taking part in the study, with patient's relatives, health care staff, managers, and also some of those people who are involved in influencing critical care policy as well.

4. Do I have to take part?

It is up to you to decide whether or not to take part. As your family have agreed to take part, some information has been collected which may be about you, such as a discussion of your illness on ward rounds. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide you do not want to be a part of this investigation, any information collected about you will be destroyed. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive.

5. What will happen to me if I take part?

This investigation will last for up to eighteen months, during this time you will be invited to participate in up to four interviews. These interviews will take place at approximately three, six, twelve and eighteen months after you have left the Critical Care Unit. They will be arranged at a time and place that is most convenient for you. You and your family members will be interviewed (although not necessarily at the same time) and you will be asked to invite an observer, such as a friend or family member, to be with you through the course of the interview.

The content of the interviews will be determined by you but it is anticipated that it will cover aspects of your experience within the Critical Care Unit. Some of the questions you may be asked are 'Tell me about your experience of Critical Care', and 'Do you recall the presence of your family?'. Should you feel that you are not ready to talk about your experiences, your part in the research will discontinue until you feel you are ready.

Before meeting you, the researcher will have collected some preliminary information about the organisation and practice of the Critical Care Unit through observation. This may well include details that the doctors and nurses have discussed about your case. If you, your next of kin or your family decide not to participate in this research, any information that has been collected that concerns your case will be destroyed.

6. What do I have to do?

During your time in the Critical Care Unit, a researcher will approach your family and ask them if they want to participate in this research. They will be given an information sheet quite similar to this one, and at a time when you are sufficiently recovered you will similarly be invited to participate. If you feel at this time you do not wish to be a part of this study then you and your family will cease to be part of the research, and information collected about you for the investigation will be destroyed. The researcher will contact you and arrange interviews for a time and place that is most convenient to you.

7. What are the possible disadvantages and risks of taking part?

There are no adverse effects anticipated as a consequence of this research. In fact, it has been found that many people appreciate the opportunity to discuss their experiences. Should you experience any emotional stress as a result of your experience in intensive care, it may be appropriate to discuss this with your family doctor (GP), who may be able to help you.

9. What happens when the research study stops?

Following the period detailed above, this research will terminate and there will be no more interviews.

10. Will my taking part in this study be kept confidential?

All identifiable information, medical or otherwise will be kept strictly confidential by the study investigator and academic staff in line with the Data Protection Act. As such it will not be made publicly available, unless its disclosure is required by law. Information obtained from this study that does not and cannot identify you individually will remain with the study investigator. It will be produced in the form of a thesis and will at a later date be published in academic and professional texts. Data concerning you will be made anonymous so you will not be able to be identified in any way. The data and information about you will be processed on a restricted access computer, and will be protected against further use or dissemination. Any information about you which leaves the hospital will have your name and address removed so that you can not be recognised from it.

11. What will happen to the results of the research study?

The results of the research study will be published in the form of a doctorate thesis, which will be available from the British Library and Cardiff University Library. Further summarised reports will be disseminated to the Intensive Care National Audit and Research Centre and the British Association of Critical Care Nurses. Additional results will be published in the appropriate academic and professional journals and oral presentations will be made to clinicians (such as senior Intensive Care staff), in addition to learned societies (such as the British Sociological Association).

12. Who is organizing and funding the research?

This study is being undertaken as part of a higher degree in research (Doctor of Philosophy) through Cardiff University, receiving academic supervision from Dr. J. Latimer and Prof. G. Williams. The initial research proposal has been reviewed by the Economic and Social Research Council (PTA-030-2002-00317) who have provided the investigator with a small research studentship in order for the investigation to be undertaken. Furthermore, it has been endorsed by senior nursing and medical staff within the ICU. They will ensure that your comfort and safety are not compromised in any way by the study. The investigator is an experienced ICU nurse, with experience in performing this type of research, and who will uphold your safety, dignity and respect at all times.

13. Who has reviewed the study?

The study has been reviewed by '***** Wales LREC' (05/WSE03/2), the Local Research Ethics Committee for the area and risk assessed by the research department of ***** NHS Trust (03/aic/1854). The Economic & Social Research Council has reviewed the research proposal from which this investigation has been based and it has received further review from academic staff of Cardiff University and senior clinical staff within the Critical Care Directorate of ***** NHS Trust. This project also appears on the NHS national research register (03/aic/1854).

14. Contact for further information.

If you have any further questions about any aspect of this study, please contact the investigator Mr P White, either in the ICU itself or through the means outlined on the front of this sheet and consent form.

The British Sociological Association and the Royal College of Nursing have published ethical guidelines which underpin this study and Consumers for Ethics in Research (CERES) publish a leaflet entitled '*Health Research and You*'. These leaflets give more information on the ethical grounding of the study and about medical research more generally. Copies of these are obtainable from the investigator on request.

Should you not wish to be a part of this study, at any stage, please inform the investigator. Irrespective of whether you have decided to continue taking part in the study, I must take the opportunity to thank you for reading this information leaflet.

SAMPLE PATIENT CONSENT FORM

The patient should complete the whole of this sheet himself/herself	(Please circle one)
1. Have you read and understood the patient information sheet? (Please take a copy home with you to keep)	YES/NO
2. Have you had an opportunity to discuss this study and ask any questions?	YES/NO
3. Have you had satisfactory answers to all of your questions?	YES/NO
4. Have you received enough information about the study?	YES/NO
5. Do you understand that you are free to withdraw from the study: <ul style="list-style-type: none"> • At any time? • Without having to give a reason? • Without affecting your future medical care? • That details of your participation up to the time of withdrawal will be stored anonymously on file and may be used in the final analysis of data 	YES/NO
6. Have you had sufficient time to come to your decision?	YES/NO
7. Do you agree to participate in this study?	YES/NO

PATIENT

Signed

Date

Name (BLOCK LETTERS)

WITNESS

Signed

Date

Name (BLOCK LETTERS)

I have explained the study to the above patient and they have indicated his/her willingness to take part.

INVESTIGATOR (Mr PJ White).

Signed

Date

(Version: PI/1[2]: 19)

Appendix Three.

Patient Information Sheet (Pilot Study).

(Retrospective consent for patients unable to consent on the commencement of the study).

Introduction.

Whilst you were unconscious, you were enrolled in an observational study which aims to examine the experience of speechlessness among intensive care unit (ICU) patients. The study has been undertaken as very little is known about the experiences patients have of their stay in the ICU, and this study aims to highlight one aspect of that experience, that of being unable to speak.

Now you are able to decide for yourself, you are invited to continue taking part, voluntarily, in this study. Before you decide, it is important for you to understand why the research is being done and what it involves. As such, the information you would have received prior to being a part of the study, were you well enough to read it, is highlighted below. Please take the time to read through the information. Should you wish to continue taking part in the study, please sign and date the attached patient consent form.

This leaflet will highlight:

- ❖ Why the study is being done.
- ❖ What will happen if you decide to take part.
- ❖ What will happen if you decide not to take part.
- ❖ The possible risks, benefits and discomforts of taking part.

Please take time to read the following information carefully and discuss it with relatives, friends if you wish. Ask the investigator, Mr Paul White, should there be anything that is not clear, or that you require more information on. Please take time to consider whether or not you wish to continue taking part in this study.

Ethical Issues.

The British Sociological Association has published ethical guidelines which underpin this study and Consumers for Ethics in Research (CERES) publish a leaflet entitled

'Medical Research and You'. These leaflets give more information on the ethical grounding of the study and about medical research more generally. Copies of which are obtainable from the investigator on request.

Sponsors of the study.

This study is being undertaken as part of a higher degree in research through Cardiff University, receiving academic supervision from Dr J Latimer, Professor G Williams and Professor B Adam. Furthermore, it has been endorsed by senior nursing and medical staff within the ICU. They will ensure that your comfort and safety are not compromised in any way by the study. The investigator is an experienced ICU nurse, who will uphold your safety, dignity and respect at all times.

What is the purpose of the study?

As a result of your illness or injury, you have had to receive treatment in an intensive care unit, often due to the failure of more than one of the bodies organs. Treatments provided in the ICU are often uncomfortable, and how people experience these treatments are often unknown. The purpose of this study is to explore your experience of receiving one particular type of treatment; receiving treatment from a ventilator. Often patients find the tube, which enables you to breathe, uncomfortable, especially when you are unable to speak to those around you. As such, the study aims to explore your experiences during the period of your treatment in the ICU, and develop an understanding of how the experience of speechlessness has effected you after you have left the ICU. This is an area of study that has been seldom investigated previously, and may benefit future patients by making the nursing and medical staff who look after patients in your position better able to appreciate their needs.

Do you have to take part?

Your continued participation in the study is voluntary, it is entirely up to you to decide whether or not you wish to continue playing a part in the study.

There may be reasons why it may not be in your best interests to continue to take part in the study. The study investigator will ask about your health, and how the experience has effected you, in order to decide whether or not you can continue taking part. It is important that you answer these questions truthfully.

You cannot continue to take part in the study if:

- ❖ You have a history of a brain condition, such as stroke or head injury.
- ❖ You have a history of mental illness, such as schizophrenia, mania or depression.
- ❖ You are under 18 years of age.
- ❖ You experience significant emotional distress as a result of your treatment in the ICU.

If you do decide to continue taking part:

- ❖ You are still free to discontinue your part in the study at any time.
- ❖ You do not have to give a reason if you want to discontinue your part in the study.
- ❖ The investigator will ask you to sign a patient consent form, and will give you a copy of the information sheet to keep.
- ❖ The study may stop at any time and for any reason, even though you may wish to continue. Should this occur, the investigator will explain the reasons why the study had to be discontinued.

What has happened so far and what will happen if you continue to take part?

The investigator will explain to you what has happened so far. The study method is referred to as an 'observational study'. This study has three main aspects to it, an initial period of observation undertaken when you were admitted to the ICU, a second period of observation which is undertaken when you are conscious but unable to speak, and the third part consisting of follow-up interviews, undertaken once you have left the ICU.

The initial period will be undertaken soon after your admission to the ICU and will continue until you regain consciousness. The aim is to develop an understanding of how those around you communicate with you. This is important, as despite being

unconscious nurses, doctors your family and friends often communicate to you and around you. Through developing an understanding of how they communicate to and around you, whilst you are unconscious will assist in developing an understanding of how they communicate when you are conscious, but unable to speak.

The second part of the study involves further observation, it builds on the first part by exploring how you communicate with those around you with the 'breathing tube' in place and how they communicate with you. For some patients in the ICU, this period can be quite frustrating, being conscious but being unable to communicate their needs effectively. It is important for the study to develop an understanding of how those around you communicate with you, and seek to draw parallels with the previous period of observation. Of course, ideally it would be appropriate to ask how you feel about being unable to speak to those around you; however, given the focus of the investigation, this would be impractical. Nevertheless, some questions which require a 'yes/no' type response may be asked which you may be able to answer by nodding or shaking your head.

The final part of the study is based on interviews with you and will be performed within three weeks of you having left the ICU. You will be asked to explain how it felt when you were unable to speak, what you remember of your time in the ICU, as well as things which made the experience better or worse. Further questions will be asked about you as a person and previous life experiences. This will enable your experience of speechlessness to be compared with significant events through your life, thereby highlighting the extent to which the experience effected you. These interviews can be quite time consuming, and given that you will be recovering from a major illness, they may be undertaken as short interviews over a number of days.

What consequences may there be for me having taken part in this study?

The majority of the first two parts of the study focus on how those around you communicate with and around you, and as such, will have little impact on you and will in no way effect the care you receive. Some informal questions will be directed to the nursing, medical staff and your family and friends about how they felt about communicating with you when you were unable to speak. Your right to dignity and privacy will be upheld at all times.

The final interview part of the study will effect you the most. First, you may experience fatigue after your illness and stay in the ICU, as such, it is important to inform the investigator that you do not wish to continue with the interview that day. Second, recalling your experience of having been a patient in the ICU may be

distressing for you. Should this occur, then again the interview will be concluded, if these thoughts effect your ability to communicate with others and keep you awake at night, it is again important that you inform the investigator in order for you to receive specialist help from the ICU follow-up nurse specialist or ICU psychologist. Having said that, many patients appreciate the opportunity to talk about their experiences, and find it helpful to speak to someone who has some idea of what they have gone through.

Will your taking part in this study be kept confidential?

All identifiable information, medical or otherwise will be kept confidential by the study investigator and academic staff. As such it will not be made publicly available, unless its disclosure is required by law.

Data obtained from this study that does not and cannot identify you individually will remain with the study investigator. It will be produced in the form of a thesis and may at a later date be published in academic and professional texts. Data concerning you will be made anonymous in order that you will not be able to be identified in any way. The data and information about you will be processed on a computer, and will be protected against further use or dissemination.

It is often important for your family doctor (GP) to be made aware of any studies you have taken part in whilst in hospital. As such, you will be asked if your GP can be informed of your taking part in this study, and with your consent, and on their request, they will receive a copy of this information sheet.

Who has reviewed the study?

The study has been reviewed by ***** Health Authority, the Local Research Ethics Committee for the area. It has received further review from Cardiff University and the Critical Care Directorate in ***** NHS Trust.

How can you get more information?

If you have any further questions about any aspect of this study, please contact the investigator Mr P White, either in the ICU or on telephone number: *****. The

investigator will give you a copy of this information sheet as well as your signed consent form to keep.

Signatures.

To continue taking part in the study, please sign and date the consent form.

The study period.

The study will commence in June and continue until August, 2002. During which time, the investigator will spend a great deal of time in the ICU, and as such will be available to answer any questions you or your family may have regarding the study.

The thesis based on this study will be submitted in September 2002.

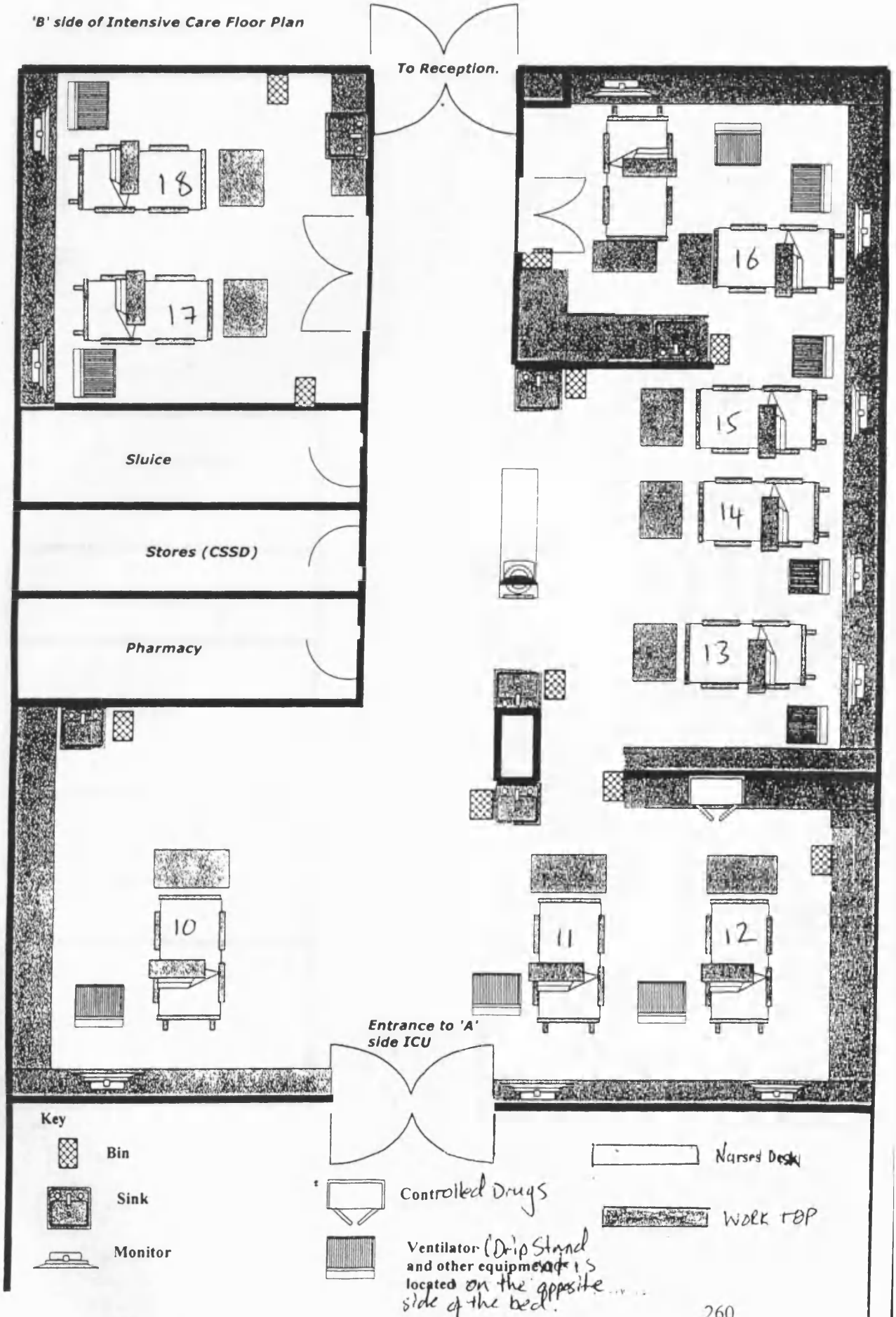
What happens next?

It may be possible to continue taking part of this study after August 2002, should you wish to do so. This will help generate information on how the experience of ICU has effected you over a longer period of time. These interviews will not necessarily take place within the hospital, but at a location which is convenient for you. Should you wish not to be involved in a larger study please inform the study investigator.

Irrespective of whether you have decided to continue taking part in the study, I must take the opportunity to thank you for reading this information leaflet.

Appendix Text

'B' side of Intensive Care Floor Plan



Appendix Four.

'A' side of Intensive Care Floor Plan

