Negotiating natural death in intensive care

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Abstract

Recent empirical evidence of barriers to palliative care in acute hospital settings shows that dying patients may receive invasive medical treatments immediately before death, in spite of evidence of their poor prognosis being available to clinicians. The difficulties of ascertaining treatment preferences, predicting the trajectory of dying in critically ill people, and assessing the degree to which further interventions are futile are well documented. Further, enduring ethical complexities attending end of life care mean that the process of withdrawing or withholding medical care is associated with significant problems for clinical staff. Specific difficulties attend the legitimation of treatment withdrawal, the perceived differences between ‘killing’ and ‘letting die’ and the cultural constraints which attend the orchestration of ‘natural’ death in situations where human agency is often required before death can follow dying.

This paper draws on ethnographic research to examine the way in which these problems are resolved during medical work within intensive care. Building on insights from the literature, an analysis of observational case study data is presented which suggests that the negotiation of natural death in intensive care hinges upon four strategies. These, which form a framework with which to interpret social interaction between physicians during end of life decision-making in intensive care, are as follows: firstly, the establishment of a ‘technical’ definition of dying-informed by results of investigations and monitoring equipment — over and above ‘bodily’ dying informed by clinical experience. Secondly, the alignment of the trajectories of technical and bodily dying to ensure that the events of non-treatment have no perceived causative link to death. Thirdly, the balancing of medical action with non-action, allowing a diffusion of responsibility for death to the patient’s body; and lastly, the incorporation of patient’s companions and nursing staff into the decision-making process. © 2000 Elsevier Science Ltd. All rights reserved.

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‘I knew when he left [the other hospital] that there wasn’t much chance, to me he more or less died here [in home town]…in the [ITU] they were only keeping him alive there artificially. I realised there wouldn’t be much chance you know…I wish now that I hadn’t agreed to, er, taking him to [ITU] and he’d just died here…I mean [he] would have loved it, being attached to all that machinery, he loved all that sort of thing you know, but the chances of him pulling through were very small.’

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I: And how do you feel about that now?

'I wish I hadn’t gone with him, I wish [children] hadn’t seen him in intensive care in the state that he was in because to me he’d died here, and he was only being kept alive artificially — I don’t think it was very fair in some respects…'

(widow: 5 months after the events reported)

Introduction

Recent empirical evidence of barriers to palliative care in acute hospital settings shows that dying patients may receive invasive and inappropriate medical treatments in the days and hours before death, in spite of evidence of their poor prognosis being available to clinicians (Faber-Langendoen, 1992, 1996; Principal Investigators for the SUPPORT Project, 1995; Ahronheim, Morrison, Baskin, Morris & Meier, 1996). The difficulties of ascertaining treatment preferences, predicting the trajectory of dying in critically ill people with complex disease pathologies, and assessing the degree to which further interventions are futile are well documented (Cook, 1997; Danis, 1998). Further, enduring ethical complexities attending end-of-life care mean that the process of withdrawing or withholding medical treatments is associated with significant problems and risks for clinical staff. Specific difficulties attend the legitimation of treatment withdrawal, the perceived differences between ‘killing’ and ‘letting die’ and the cultural constraints which attend the orchestration of ‘good’ and ‘natural’ death in situations where human agency is often required before death can follow dying.

This paper draws on ethnographic research that studied the way in which death and dying are interpreted and managed within two general adult intensive care units in the UK. The paper focuses on one aspect of the wider study, examining the way in which problems of definition between euthanasia, withdrawal of treatment and natural death are resolved during medical work within intensive care¹. The study was premised on the argument that the study of the management of death within intensive care units captures, reflects and lays bare for analysis issues of critical concern and relevance to debates about end-of-life decision making, given that 70% of deaths in such environments occur after a non-treatment decision (Winter & Cohen, 1999). Analysis of data from the study was informed by an extensive literature review of the ‘problem’ of non-treatment decisions in intensive care. The resulting analysis builds on insights gleaned from a range of disparate sources and posits an explanatory framework within which the processes of social interaction during end of life decision making may be interpreted.

Non-treatment decisions in intensive care: insights from the literature

Critically ill individuals with a complex mix of acute and chronic pathologies are admitted to intensive care. Of those, between 15–35% die during intensive therapy (Koch, Rodeffer & Wears, 1994; Metcalfe & McPherson, 1994; Gunning & Rowan, 1999), and formal medical decisions to limit or withdraw treatments habitually precede death (Smedira et al., 1990; Koch et al., 1994; Simpson, 1994; Searle, 1996; Winter & Cohen, 1999). This mirrors a trend visible in the management of death within other hospital areas (Faber-Langendoen, 1992, 1996; Pijnenborg, van der Maas, Kardaun, Glerum, van Delden & Looman, 1995). In spite of increasing incidence, little is known about the process of withdrawing or withholding medical treatment. Winter and Cohen suggest however that ‘…the timing of withdrawal, the treatments withdrawn, and the manner of withdrawal may vary considerably, not only from country to country but also between intensive care units in the same country’ (Winter & Cohen, 1999, p. 306).

One reason for variation between countries comes from differences in the law surrounding end of life decision making. A major difference between the UK and the USA, for example, rests upon the concept of surrogacy for patients who are too ill to be able to make informed autonomous decisions about their own treatment. In some American states, a designated chain of surrogacy exists and it is a legal obligation of clinicians to consult with the designated surrogate before making any treatment decision. In the UK, relatives have no legal right of surrogacy, although recent guidance on end of life decision making from the British Medical Association (1999) probably reflects current practice in its advice that relatives have a pivotal role to play in informing the deliberations of clinicians about patients’ best interests, capacity to benefit and quality of life.

Some evidence is available which suggests that differences in processes of decision making between intensive care units in the same country may be due to
organisational and cultural norms that develop. These influence the manner in which non-treatment decisions are approached and enacted. Thus, in a comparative study of two intensive care units in the USA, Zussman (1992) demonstrates that the physicians in one unit not only made non-treatment decisions more frequently, but also followed a more decisive style in implementing those decisions. Zussman draws on the early work of Sudnow, who observed how staff interact on the basis that ‘death must be made to seem an outcome of dying’ (Sudnow, 1967, p. 95), and describes how some 30 years later:

‘In the face of uncertainty, physicians struggle to maintain discretion. They do so, in part, by conceptualizing both the course of the illness and the types of treatment in terms that allow wide latitude in judgements as to what constitutes ‘appropriate’ action. This strategy is evident in the ways physicians conceptuallize ‘terminal’. It is also evident in the distinction they make between ‘aggressive’ and ‘unaggressive’ treatments.’ (Zussman, 1992, p. 123).

In a comparative ethnography of intensive care and obstetric settings in the UK, Harvey (1997) sheds further light on the variation in action and approach to non-treatment decisions, describing how clinical staff in intensive care engage in a strategic practice of withdrawing life support slowly in order to mimic the decline of ‘natural’ death and in accordance with culturally prescriptive norms about the proper course of ‘natural’ dying. Similarly, Slomka (1992) describes the ‘bargaining’ or ‘negotiation’ process which occurs at the bedside of a critically ill person. Such bargaining defines the meaning of medical technology, and helps to decide ‘how far medical technology should go in prolonging life or in prolonging death’ (Slomka, 1992, p. 251). Slomka points to the way in which moral responsibility for the patient’s death by withdrawing treatment is shared with family members, while the moral responsibility for the patient’s death by withholding treatment is displaced to the patient.

In an study of the use of resuscitation procedures and equipment in the construction of ‘dignified death’ in the emergency room, Timmermans (1998) notes the complex intersection between human agency and technological power in western secularised cultures in which resuscitation techniques have become incorporated into a dense pattern of cultural beliefs about death with dignity. In this patterning of beliefs, rather than technology being imminant to dignified death, it takes a central role in the procurement of dignity in the event of sudden, traumatic deaths and is used to make sense of deaths that might otherwise seem meaningless. This can lead to variation in practice according to the particular circumstances in which death occurs, and according to the motivations and understandings of those involved in resuscitative attempts.

Against the backdrop of culturally and morally prescriptive ideas about ‘natural’ death, the role of technology in this event and the part played by different actors, extensive concerns have been expressed by clinicians regarding the legal and ethical implications of such issues. Most frequently expressed is a concern over the philosophical ‘shades of grey’ that surround the distinction between euthanasia and withdrawal of treatment. This has been described as the distinction between ‘killing and letting die’ (Rachels, 1975; Johnson, 1993; McMahon, 1993; Cartwright, 1996). The uncertainty surrounding the distinction has led to attempts to ensure that there is no ‘proximate relationship’ (Hoyt, 1995, p. 621), or apparently causative link, between the withdrawal of life support and death. A central aspect of this discussion is the difficulty of predicting whether or not a particular course of action is prolonging inevitable death or facilitating all the chances for ‘meaningful’ recovery.

In an early commentary, Jennett framed the essential dilemma in intensive care as ‘the vicious circle of commitment’ (Jennett, 1984, p. 1709), pointing out that the withdrawal of therapy even when it is agreed that the prognosis is ‘hopeless’ is very much more difficult than taking the decision not even to start such treatment. These complexities are conjoined with a developing awareness among the medical profession that their decisions about the treatment of individual patients or groups of patients may be the subject of challenges from various sources. Such challenges may at times be paradoxical. Thus demands for freedom from medical intervention, perhaps expressed as desires for ‘living wills’ or ‘advance directives’, may, at the same time, be paralleled by other demands that doctors preserve life indefinitely. The concept of ‘futility’ has been employed to describe a scenario in which pressure is exerted on physicians to continue treatment by the companions of fatally ill individuals (Schneiderman, Jecker & Jonsen, 1990; Teres, 1993; Hoyt, 1995).

One response to the complex management of non-treatment decisions has been to analyse and discuss the ethical principles on which modern medical practice is based and apply these to the discussion of life and death issues in intensive care (Task Force on Ethics of the Society of Critical Care Medicine, 1990). This approach, together with the legal precedents that have emerged from celebrated cases has led to the development of guidelines for use in practical situations. Such guidelines are relatively common in the USA, and reflect a growing move towards surrogate decision making in that country (Wanzer, Adelstein & Cranford, 1984; Nelson & Nelson, 1995). In the UK, guidelines have emerged following the ‘increasingly fine line’ (Bennett, 1995) identified in cases such as Airedale...
NHS Trust vs Bland (1993) between extraordinary and ordinary treatment. For example, following this particular case a ‘Practice Note’ was issued by the Official Solicitor which outlines general principles of law as applied to the withdrawal of all forms of treatment from individuals who are diagnosed as being in a persistent vegetative state. Most recently, the British Medical Association has published advice about the withdrawal and withholding of treatment (British Medical Association, 1999). However the extensive legal documentation that surrounds end of life decisions in the USA is largely absent in the UK. Bayliss identified this difference as early as 1982, and related it to a variety of cultural and social factors. Of these, he identified the developing culture of ‘distrust’ of medicine in the USA as a central contributor to public ‘litigiousness’ (Bayliss, 1982, p. 1374).

The emergent culture of ‘risk’ and the extensive attempts to clarify the legal and ethical issues surrounding non-treatment decisions may be related to attempts to develop what some commentators call ‘the science of prognosis’ (Searle, 1996, p. 291). Such attempts involve the subjugation of the ‘art’ of medical decision-making concerning individual patients to ‘scientific guidelines’. The growth of evidence based medicine is one preeminent example of this contemporary pre-occupation. Gordon gives a comprehensive review of this trend in medicine, and describes how the ‘personal power and private magic’ (Gordon, 1988, p. 257) invested in the clinical judgement of the individual physician has come under attack, with physicians being asked to ‘make themselves and their practice more visible’ (Gordon, 1988, p. 257). This involves the application of theories of decision analysis, of epidemiology and of probability, to clinical judgement about individual patients. In intensive care, the trend towards developing severity of illness scores as a predictive tool is a specific illustration of this more general theme (Gunning & Rowan, 1999), as are attempts to eradicate the ‘prognostic disagreement and inaccuracy’ (Poses, Bekes, Copare & Scott, 1989, p. 827) caused by the idiosyncratic values, beliefs and habits of individual physicians (Poses et al., 1989; Christakis & Asch, 1993).

This study focuses on the conduct of medical decision making at the bedside of critically ill people, and reveals medical work with dying people in intensive care as an interactional accomplishment which achieves balance between the disparate tensions and constraints encapsulated in the literature presented above. Case study data are presented which suggest that clinicians negotiate ‘natural’ death in intensive care by means of complex interactional strategies in which the timing of treatment withdrawal is carefully planned, and is accompanied by expressions of belief about the causation of death and the distribution of responsibility for decision-making between clinicians, patients, nurses and family members. The analysis highlights the existence of two potentially divergent dying trajectories, ‘technical’ and ‘bodily’ dying, which must be aligned in order for death to occur at the ‘right’ time. Containing and preventing divergence between bodily and technical dying are represented as the basis of ‘nature taking its course’ and ‘natural death’ in intensive care.

Research methods

The wider study (Seymour, 1997) from which this paper is drawn consisted of fourteen detailed case studies, each of which followed the course of an individual’s critical illness from shortly after admission to intensive care, to beyond death or recovery. The case studies were compiled by ethnographic methods in the intensive care units of two hospitals in one large city during 1995 and the first two months of 1996. Each ‘case’ consisted of the interactions and perceptions of the health care staff and designated next of kin involved with the selected critically ill individual. Eleven individuals died during the course of the research, eight of which died following a withdrawal of some aspects of their medical treatment.

The case study approach was used for ethical reasons and to allow the detailed examination and representation of individual experience and group interaction within its social context. Such an approach limited the observational ‘range’ to events concerning the selected patients and thus was more suited to the sensitive and emotionally charged nature of such a setting. Intensive care patients are unable to give consent or make choices about who participates in, or observes, events surrounding them. For this reason, consent for focused observations was sought from surrogates for the patient: both their designated next of kin and members of their health care team. The critically ill individuals at the centre of each case study were selected purposively (Strauss & Corbin, 1990) so that those at highest risk of death were followed.²
Observational, documentary and interview data comprising each case were analysed and cross-compared using qualitative techniques. A detailed case study report was written which attempted to ‘capture’ all the data relevant to that case. Each case was then compared with other cases to establish similarities, differences and patterns within the data as a whole. This process was akin to that of ‘constant comparative analysis’ (Glaser & Strauss, 1967) or ‘inductive analysis’ techniques (Denzin, 1978) discussed in grounded theory writings.

Negotiating natural death

The data from this study suggest that the active construction of ‘natural death’ during medical work involves, in part, the invocation and exchange of cultural ideas about ‘good death’ and ‘nature taking its course’. For example, during participant observation the following exchange was witnessed between a consultant anaesthetist and the family of a dying man. The consultant is explaining possible plans for a withdrawal of ventilator support:

(from field notes)

... ‘We could do a small operation called a tracheostomy which would enable him to keep his airway clear and enable him to breathe more easily. We could decide to remove the ET [endo-tracheal] tube. We know that he can breath because we disconnected him from the ventilator during the ward round today — and see how he gets on. If we took this course then we would let nature take its course. We would not replace the tube and we would not treat any pneumonia that may develop...’

However, the data suggest that ‘natural death’ is primarily constructed during medical work by means of four interactional strategies. These centre around timing, causation and responsibility and are; firstly, the establishment of a ‘technical’ definition of dying — based on blood results, monitoring evidence and investigation — over and above ‘bodily’ dying, based on the habitual recognition of the senses and informed by clinical experience. Such definition occurs across a variable time period and involves the active negotiation and re-negotiation of the meaning of medical–technical data. Secondly, the alignment of the trajectory of ‘known’ technical dying with the development of ‘seen’ and ‘felt’ bodily dying. It is this alignment which ensures that the events of treatment withdrawal are seen to have no directly causative link to death. Thirdly, the problem of causation is further dealt with by a strategic balancing of medical action with medical non-action. This allows for a diffusion of responsibility for death to the body of the ill person, with the body defined as no longer able to take advantage of medical technology. Lastly, medical work is directed, where circumstances allow, towards the incorporation of patients’ companions and nursing staff into the decision making process. These strategies, which enable clinicians to draw dying and death into the ‘production’ (Atkinson 1995) of ‘rational science’ and at the same time respond to a complex range of ethical issues and cultural beliefs concerning death, were visible in varying degrees of emphasis in all of the eight cases observed in which death followed a non-treatment decision.

This paper analyses the relationship between medical staff and the patient’s body, and examines the way in which the first three identified strategies were carried out. Data relating to the fourth strategy, where the role of the nursing staff and the patient’s companions is pivotal, will be reported separately.

The style of reporting here reflects a deliberate choice made at the outset of the wider study to identify general issues and concerns impinging on the management of intensive care patients, but to then explore these through the analysis of detailed portrayals and accounts of particular ‘critical’ cases.

Two contrasting examples will be drawn from the case study data. The extracts from the first case illustrates how the definition of dying hinges upon achieving agreement about the meaning of medical treatment and of medical–technical data. As shown in this case, such agreement evolves across time; several days elapsed in this particular example before agreement was reached. It illustrates how ‘intuitive’ accounts of ‘bodily dying’ are subsumed to the ‘scientific’ analysis of ‘technical’ dying. The second extract is similarly illustrative of a negotiated definition of dying, but focuses more closely on the way in which medical action is balanced with non-action such that ‘natural death’ occurs.

Case study 1

This first case concerns ‘John’, who was admitted to intensive care for treatment for gastro-intestinal bleeding, liver and lung disease. He had developed cardiac failure shortly after his admission. During his nine days in intensive care attempts were made to establish a cause for his intestinal bleeding and to treat his developing lung and cardiac failure. John received ventilation and drainage of a pleural effusion, together

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3 Italics have been used to denote extracts from observational fieldnotes, or to make an emphasis in the text. ... denotes a deleted passage, except where it occurs at the beginning of a quote. - - denotes a pause in speech.
with cardiac monitoring and drug support. A gastroscopy was performed soon after his admission to assess his gastro-intestinal bleeding, and he received multiple transfusions of bloods and clotting factors. Due to the gravity of his overall condition, he was deemed unsuitable for surgery within the first two days of his treatment. Following a diagnosis of adult respiratory distress syndrome, continuous veno-venous haemofiltration (similar to dialysis and known as ‘CVVH’) was commenced on day three. This was used in an attempt to reduce the severe pulmonary oedema and heart failure from which John was suffering as a result of the disease process in his lungs. The continuous veno-venous haemofiltration had to be discontinued when his cardiovascular state deteriorated rapidly. John was nursed in a prone position for periods in an attempt to maximise his lung expansion and oxygen exchange but was transferred to a kinetic bed (an automatically tilting bed) because of difficulties in observing him for bleeding in that position. Sedative and paralysing agents were administered at all times to enable John to tolerate these treatments. When his cardiovascular condition continued to deteriorate, decisions were taken that he was not for resuscitation, for re-institution of continuous veno-venous haemofiltration, or for more complex ventilatory procedures. These decisions were taken on day six. Following further intestinal bleeding and development of an intractable cardiac arrhythmia over the course of days eight and nine; cardiac drug support was withdrawn from John. He died during the afternoon of day nine. We join the case on day four.

The following extract comes from the fieldnotes which were taken on that day after the ward round. The notes illustrate how the medical staff consult and negotiate with one another in trying to establish a course of action. Sometimes the consultation is part of the education of junior medical staff, but it also enables the ‘smoothing out’ of differences of opinion between doctors of equal status, or of different specialties, as to the likely response to a particular therapeutic option. The extract below can be seen as an active construction of the nature of John’s illness, in which negotiation over the meaning of medical–technical data and of the technical treatments given to John runs parallel to, and has to be aligned with, the less easily articulated but clear recognition of inevitable bodily dying. Most noteworthy is the discussion between two consultant anaesthetists, Consultants ‘B’ and ‘C’, who struggle to establish a course of action which is scientifically valid but also in keeping with their ‘intuitive’ recognition of inevitable death. The discussion between them concerns whether John is suffering from multiple ‘three system’ organ failure, (recognised as a crucial indicator of the statistical probability of death), and the extent to the continuous veno-venous haemofiltration is alleviating or aggravating his heart and respiratory failure. The consultants argue for fifteen minutes, trying to interpret highly technical data and agree on a course of therapeutic action, before asking another doctor to settle the disagreement:

(From the fieldnotes day four)

14:15 — Consultant C’s ward round.
John’s family have gone out. Nurse R presents the case. Consultant C listens and looks very grave and concerned. ‘This is a very complicated case, what do you think we should do?’ (This is directed to the senior registrar and the registrar.) The senior registrar hesitates, the registrar doesn’t answer, but she laughs nervously. Consultant C in response to this says: ‘No, you can’t consider withdrawing, he only has two system failure — heart and lungs — so what do we do? Are you waiting for me to say?’ They assent to this by nodding. Consultant C: ‘Well, I think we should stop the CVVH and give him a big bolus of fluid. He has a tachycardia, a low bp [blood pressure] and a low wedge [indirect measurement of left heart pressure] which has not responded to adrenaline or dobutamine. Give him 500 ml of hespan and 500 ml of HAS [both colloid solutions] and we will retrack [measure physiological data] him at 16:00.

Nurse R: ‘Shall we stop the CVVH now?’

Consultant C: ‘Wait for a bit — I think it should come off, but I need to discuss it with Consultant B’ (who is not there, and who had been adamant that the CVVH should remain — I wonder whether this accounts for the nervousness of the registrar and the senior registrar.)

14:45 — The surgical senior registrar and lecturer appear. They sit and read John’s file and then go behind the curtains to examine him. They question nurse R as to his condition. Just then Consultant C comes out of the side-room, sees them and comes across to speak to them. There is some discussion about his liver function and the presence or not of varices: ‘I didn’t see any on scope’ and: ‘I don’t believe all of this written in the notes’ and ‘Has he had a splenectomy or not?’ There is much rustling of paper, trying to make sense of previous notes. The surgeon then says that in his opinion there is still no possibility of surgical intervention at the moment because of his poor state and that it is not clear that he needs surgery anyway, since they still do not really know what is wrong with him. Consultant B appears at the end of this discussion and
Consultant C says to Consultant B: ‘I think he is intravascularly dry, so I am loading him with fluid — it’s had an effect already, and I’d like to take him off of the CVVH now.’

Consultant B — looking unhappy and very concerned — ‘The problem is that the colloid doesn’t stay where we want it to for long, it moves into the interstitial space and then we are back to where we started. I think we need to fill him, but take off fluid at the same time.’

Consultant C: ‘I agree with you, but I feel that he crashes [becomes severely hypoxic and hypotensive] on being put onto CVVH — it’s too aggressive. He is peeing — we should rely on that. Dr X always says; if one thing doesn’t work try something else and if that works, pursue it. I mean each patient is different, they do not respond in a predictable, linear way to intervention.’

Consultant B: ‘Yes, I can’t disagree with you — it’s just that, well, I just feel, we should keep the CVVH going, theoretically it should work.’

Consultant C: ‘What we are debating is the whole crux of ITU medicine — intravascular vs interstitial fluid movement. Basically, no one knows what it is best to do.’

Consultant B: (turns to the senior registrar who has been listening while taking blood and collecting data for the ‘tracking’): ‘What do you think Dr…?’

Senior registrar: ‘Well, he’s very poorly.’ (smiling) Hoots of laughter all round.

The senior registrar becomes more serious: ‘…but I think he has responded to fluid and we should take the CVVH off.’

Consultant C (lowering his voice): ‘Look, we all know that this man is going to die — he has all the hallmarks, we all know the ones who don’t make it — but he only has two system failure, lungs and heart, so we’ve got to carry on trying — I don’t think it will do any good.’

‘Consultant B: ‘I agree with you, I think he will die, but we’ve got to carry on trying.’

The use of humour has the effect of undermining the extensive technical debate and legitimating ‘intuitive’ beliefs that John will almost certainly die. It allows the consultants to express to each other their private recognition of the likelihood, indeed the certainty, of John’s bodily dying. However, in spite of this sudden expression of resistance to medical-technical discourse, they are unable to justify action on the basis of ‘seen’ bodily dying. Full treatment is continued. John’s condition stabilises briefly over the course of day five, but he suffers a further episode of acute deterioration during the early hours of day six. The consultants featured in the earlier exchange are now off duty and the management of John’s care has been delegated to the on-call consultant, senior registrar, and the registrar. The following extract from the fieldnotes demonstrates the way these individuals achieve a re-definition of the John’s clinical data which enables them to justify decisions to withhold particular types of treatment from him:

(From the fieldnotes day six)

Senior registrar: ‘I just feel that we’re going nowhere. He is on maximal support, and I just think he is going to die. I believe that he would have a less than 10% chance of survival if he only had a lung injury of the type he has, without all of the other problems.’

Registrar: ‘The problem is Consultant B; he does not want us to withdraw on this man. He says that as there is only two-system failure we should continue treatment — look it’s written here.’ All three read the ‘file’ [medical notes].

Senior registrar: ‘Well, I think he has liver failure as well.’

Registrar: ‘That hasn’t been such a problem apparently.’

Consultant: ‘Let’s have a look.’ (he turns to the biochemistry and haematology results flow sheet)

Senior registrar: ‘Look! How can it be said that he is not in liver failure with figures like that! (He points to the bilirubin and plasma protein results)

Consultant: ‘OK, we all know that this man is going to die, but it depends on how far you want to push it. You could argue the toss with Cons B, or you can decide not to do certain things. Are you going to CVVH him if he develops renal failure for example?’

Senior registrar: ‘No.’

Consultant: ‘Right, OK, are you going to jet him?’ [This unusual ‘last chance’ form of artificial ventilation was discussed earlier as a possible option]
Senior registrar: ‘There is no point because his prognosis is so appalling.’

Consultant: ‘Right, he is on maximal support already then. I don’t think it’s a question of withdrawing that. Will you resuscitate him if he arrests?’

Senior registrar: ‘There won’t be any point, he won’t recover.’

Consultant: ‘So, he’s not for resuscitation. There is nothing more that you can do.’

This ward round has the effect of extending the limits of medical action from surgical intervention to the more fundamental technique of resuscitation. This limitation hinges upon the diagnosis of liver failure, which removes John from the realms of the potentially salvageable ‘two-system’ failure category, into the potentially unsalvageable ‘three-system’ failure category. The manner in which haematological and biochemical data are debated reveals clearly that such figures are open to various interpretations according to the standpoint of the individual reading them. In this way, the intuitive knowledge based on past clinical experience—‘we all know this man is going to die’—is gradually aligned to the demonstrable technical and bio-medical data, and the conditions which allow them to devise a plan of non-action are established. The medical support he is already receiving becomes defined as ‘maximal’ and the duty consultant is able to reassure the senior registrar and registrar that ‘there is nothing more you can do’.

The following day (day seven, when Consultant B is back on duty) there are further discussions relating to the haematological and biochemical data, again indicating the variability of interpretations that are possible on the basis of such data, and the differential evaluations that can be made when such figures are ‘read’ alongside the results from other diagnostic investigations. At this point, Consultant B persists in his opinion that John’s liver function is ‘holding its own’, and instead concentrates on the severity of his lung disease as demonstrated by the series of chest x-rays available. This difference in opinion means that while the plan for non-action outlined above is adhered to; there is no withdrawal of treatment from him until a further acute change occurs in his condition. This change takes place on the evening of day seven, when John suffers a re-occurrence of gastro-intestinal bleeding, and develops a serious cardiac arrhythmia. He suffers further bleeding across the course of day eight, and the accompanying atrial fibrillation becomes intractable. On the afternoon of day nine, after John’s wife has been contacted and has arrived to be with him, the cardiac drugs he is receiving are switched off and his oxygen reduced. He dies shortly afterwards.

The trajectory of John’s death is relatively slow. Negotiation takes place across the course of several days and there is a gradual movement from ‘full’ treatment, to withholding treatment, and then finally to ‘withdrawal’. The latter only occurs when it becomes clear that death will occur in spite of any further treatment manoeuvres. In this way a causative link between non-treatment and death is avoided, and ‘bodily’ death is aligned to ‘technical’ death. So it is that ‘natural’ death is successfully constructed.

The next example demonstrates the problems of constructing ‘natural death’ in a situation where a much more rapid, acute bodily deterioration occurs. The data discussed here are drawn from the case of ‘Richard’, a young man who had been fatally injured in a road traffic accident and who died after seven days in intensive care. In Richard’s case, ‘bodily’ death threatens to outpace the evolving process of negotiation that is necessary to confirm ‘technical’ death and to allow treatment withdrawal to precede bodily death. In this situation, particular efforts are employed to ensure the ‘balancing’ of medical action and the distribution of responsibility between members of the medical team, and between them and Richard’s body. It is noteworthy that this case involves a much younger man, who had previously been fully fit. His youth and ‘fitness’ appear to play a large part in the reluctance to stop medical treatment.

Case study 2

We join Richard’s case on the morning of day seven, just over six hours before his death. The previous afternoon there had been a sudden and severe deterioration in his condition due to internal bleeding. I arrive in the unit at 08:45. The senior registrar and the registrar are in the staff room and I speak to them, asking how Richard is:

(from the fieldnotes day 7)

The senior registrar shakes his head: ‘Dreadful, dreadful.’ I go through to the unit and the senior registrar follows, speaking to me: ‘Have you seen his face yet today?’ The curtains are around the bed. I say that no, I haven’t.

Senior registrar: ‘Well, he looks dead, I mean he is dead to all intents and purposes — but I can’t do anything yet — we’ve tried reducing the vasopressin to give him a bit more peripheral perfusion, but his colour is still just awful - - you press his skin, it blanches and then very, very sluggishly there is some colour, but it’s a blue yellow colour rather than red. I’m going to have to wait until Consultant
C does his round, and then we’ve got to step back from this.’

Richard, in the ordinary ‘bodily’ sense, has died, but in this ‘extraordinary’ environment, it becomes the responsibility of the medical staff to ‘allow’ this to happen on the basis of a technical definition. The medical hierarchy that exists means that the senior registrar cannot act on what he sees and what he feels to be true; he must wait for the duty consultant to legitimate this.

Over the next few hours activity continues around Richard in much the same way as the other patients. However the faces of the staff as they work are grim and they are almost silent.

Consultant C arrives at 12:15. He immediately telephones the surgical consultant to come and see Richard. The exchange that follows shows how the consultant surgeon and consultant anaesthetist communicate their definition of Richard’s condition to each other through an exploration of the boundaries of their individual responsibilities, and the part that Richard himself has had to play in events. The exchange ends with a re-working of the situation, not as failure, but as the best that could have been achieved in the circumstances:

(from the fieldnotes day 7)

Consultant C (to the surgeon): ‘Our major problem is that he has a severe metabolic acidosis with a pH of 6.9, and a base excess of −26, [showing cellular hypoxia] in spite of everything we are doing and in spite of a normal P0₂ [arterial pressure of oxygen].’

Surgeon: ‘Why do you think he has gone off then?’

Consultant C: ‘Well it’s basically to do with shunting - - we can deliver the oxygen to him but he is not able to use it and so the body organs gradually die off.’

Surgeon: ‘If there was a surgical cause - - if by decompressing his abdomen that would make a difference, then I would be prepared to intervene, but from what you are saying it will not do so?’

Consultant C: ‘Well, no, his abdomen is more distended, but he will die if we take him and he will die if we leave him like this anyway for a day or so. I will of course look at everything this afternoon, x-rays, blood results, etc, but I really think we have to accept that he is not going to survive and make a decision to take his drive [cardiac drugs] off. The relatives are not here at the moment, so we will have to wait.’

Surgeon: ‘Well, it’s just a tragic case. All you can do with such a young man is everything you can think of. You’ve done well to keep him alive for a week - - not that it is of any comfort I don’t suppose.’

The consultant presents the ‘problem’ as belonging to the intensive care medical staff describing it in complex physiological terms. In asking for clarification: (‘why has he gone off then?’) the surgeon relocates the ‘problem’ as belonging to Richard. The consultant responds by drawing the boundary around the expectations that can be held of his treatment: ‘We can deliver the oxygen to him, but he is not able to use it.’ Having checked that surgical intervention will not improve the situation, the surgeon acquiesces to the proposal to withdraw Richard’s cardiac drugs and then quickly offers a definition of the situation that supports the actions taken over the last week as ‘all’ that could have been done: ‘You’ve done well to keep him alive for a week’. With his family sitting beside him, Richard’s drugs are switched off. He dies five minutes later, seven days after his accident.

Discussion

Both of the case studies presented reveal the existence of an intricate and dialectical relationship between the trajectory of ‘seen’ bodily dying and the discursive negotiation of ‘known’ technical dying: a critical basis of social order during medical work within intensive care. The relationship between the ‘materially’ dying body and the ‘negotiated’ dying body threatens divergence constantly and must be contained in order for timely and ‘natural’ death to be achieved. The threatened divergence between bodily and technical dying reflects how contemporary death and dying are surrounded by what Hockey has referred to as the ‘fusion and confusion’ (Hockey, 1996, p. 14) of medical technology and ‘nature’: during death, medical technology becomes constitutive of ‘the natural’ in so far as it frames and determines perceptions and thinking about the way things should happen (Seymour, 1999). Further, while the construction of the ‘natural death’ is tightly bounded by the framework of widely accepted principles of end of life ethics, these are principles that are subject similarly to interpretation and re-interpretation during social interaction. We see here affirmation of Armstrong’s assertion that: ‘death is not a thing or event simply existing independently of human consciousness; it is simply the word given to a certain threshold, interface, point of separation’ (Armstrong, 1987, p. 155).

The presence of the ‘material body’ in this data, and the evidence of its profound influence on the character
of social interaction, address a space within sociological theory (Turner, 1996). Here we are able to see how the ‘body’ as a corporeal reality impinges upon the socially constructive work of medicine. Rather than the ‘body without organs’ (Fox, 1993, p. 24), which is discursively malleable in almost infinite ways, the ‘body with organs’ is shown to play an active role in constraining and directing the clinical discourse of which it is a subject. Further, in this analysis, medicine is revealed as enacted by thinking, feeling individuals who may, at times, actively resist the conforming pressures of mainstream clinical ideology. As Lupton has argued,

‘...subjectivity may be understood as dynamic and contextual rather than static, and as often fraught with ambivalence, irrationality and conflict...people are often complicit in the reproduction of medical power as well as seeking to challenge it’ (Lupton, 1997, p. 106).

Intensive care reflects the modern preoccupation with the mastery of disease and the eradication of ‘untimely death’. It is the place to which clinicians may refer a patient when that individual stands at the brink of death and is beyond the reach of conventional therapies. Unravelling the nature of complex disease and predicting its outcome is complicated by a lack of previous familiarity between health care staff and the patient, by the unconscious state of the ill person (Müller & Koenig, 1988), and by the advanced technical abilities of modern medicine to blur the boundaries between living and dying. Further, it is acknowledged that in spite of efforts to diminish any distinction between withholding and withdrawing treatments (British Medical Association, 1999), the process of withdrawing treatments once instituted is emotionally fraught and subject to many difficulties. At the centre of these debates are the proper role of medicine and medical practitioners at the end of life, and a current climate in which most doctors are keen to distance themselves from any actions that might be interpreted as active euthanasia (Johnston & Pfeifer, 1998). At the same time, an argument has been developed (Hopkins, 1997) which suggests that withdrawing treatments, in order that a recognised process of dying may replace any artificial prolongation of life, is morally no different to active euthanasia:

“In looking at actions which count as “passive” and which actually counts as “active” it is clear that the practice of euthanasia consistently revolves around notions of a “natural” death, the “natural” course of disease, and the contextual permissibility of “unplugging machines” and “withdrawing treatments”. Subtly but crucially evident in these concerns is a conceptual reliance on a form of the nature/culture distinction — the distinction between the “natural” and the “artificial” — and on particular assumptions about the definition and moral relevance of technology” (Hopkins, 1997, p. 29).

The answer to the question of why individual patients may frequently receive protracted and costly multiple organ system support in the hours and days immediately before death (Singer, 1994; Principal Investigators for the SUPPORT Project, 1995; Faber-Langendoen, 1992, 1996; Bion & Strunin, 1996), even when death is recognised as certain, lies it would seem, within this paradox of what constitutes natural and artificial in a highly technologised society at the start of its third millennium. It is recognised increasingly that most deaths are managed in some way (Ashby, 1998); what we lack is knowledge about the process of that management with which to inform and improve care at the end of life.

Focusing on the intricacies of social interaction in the specialised environment of intensive care has, it is hoped, shed light on the way in which the paradox of ‘natural’ and ‘artificial’ is dealt with at the bedside and how the disparate understandings of medical ‘science’ and clinical wisdom are reconciled. Further, an analytical framework has been presented which may be of value in elucidating the complex processes that underpin the deferral of death and dying in high technology areas of health care. The difficulties that face clinicians during the course of their everyday work with critically ill and dying people must be allowed to further inform our thinking about the ‘modern myth’ of natural death (Hopkins, 1997) if ‘death with dignity’ is to become a reality in our health care systems. As Ashby notes, until better understanding is reached and greater debate encouraged about the management of end-of-life care, it will remain the case that clinical behaviour will range from ‘...abrupt cessation of treatment, minimalist palliative care and treatment directed at bringing about a rapid dying process, to excessive caution about being seen to be instrumental in causing the death’ (Ashby, 1998, p. 74).

4 This philosophical argument hinges upon a particular conception of causation. Hopkins argues that the withdrawal of artificial treatments (as opposed to the underlying disease process) causes death, and therefore there is no difference between withdrawal of such treatments and the administration of an artificial treatment (such as a drug) designed to achieve euthanasia. For a detailed discussion of causality and its role in end of life decision-making see Ashby (1998).
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References

Principal Investigators for the SUPPORT Project (1995). A controlled trial to improve care for seriously ill hospital-


