

Conflict rationalization: How family members cope with a diagnosis of brain stem death.

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Abstract

Brain death, whether it be brain stem death [UK] or whole-brain death [USA] is a prerequisite for heart-beating organ donation. Understanding how brain death is perceived by family members approached about organ donation, its significance to them, and if it is accepted by them, are, therefore important issues to explore as biomedicine expands the range of end of life technologies that blur the demarcation between life and death. To explore the concept of brain stem death and its meaning to family members the following research questions were posed: i) What does the diagnosis of death based on brain stem testing mean to bereaved family members who have been approached and asked to consider donation from a deceased relative, and ii) How do family members understand the concept of brain stem death. To address these research questions a secondary analysis of 28 interviews sorted from two primary datasets was carried out. The primary datasets contained longitudinal and cross-sectional interviews carried out in the UK with family members who had been approached about organ donation and agreed to donate their relatives' organs. Data analysis was guided by Charmaz's Constructionist grounded theory method and resulted in the theory of Paradoxical Death, a process whereby family members and health professionals engage in a series of practical and psychological activities aimed at rationalising real or potential emotional and cognitive conflict resulting from a diagnosis of death that is brain-based, whilst faced with the physical image of a functioning body. Rationalising emotional and cognitive conflict is how family members and health professionals appeared to process this paradoxical death, a death that is contrary to conventional opinion.

Introduction

Authors [Youngner et al, 1999] suggest that to diagnose death there needs to be a definition of death. The definition of death that was accepted until steps were taken to change it in the mid 1960s, was based on cardiopulmonary criteria "The organism is alive only when the vital bodily fluids, air and blood, continue to flow through the organism" [Brody, 1999:73]. The significance of air and blood in death can be traced back to early civilisations. The departure of the soul from the body as a marker of death was central to the ancient Egyptian civilisation and influenced the later Greek, Hebrew, Islamic and Christian concepts of death [Pallis and Harley, 1996]. Classical Greek physicians gave prominence to the role of the heart in the diagnosis of death: they believed "the heart alone served as the seat of life" and that while death could begin in the lungs, the lungs served merely to support the heart

[Pernick, 1988:19]. Early Hebrew scholars believed that man [sic] was made in the image of God and that when the spirit of God [ruach or Greek, pneuma] was taken away, then man was no more [Eckardt, 1972]. Therefore *ruach* [can be translated as soul] or breath was primary in determining death as it marked the soul leaving the body.

The influence of these ideas is seen in later definitions of death such as that in *Black's Law Dictionary* [4th Edition, 1951], where death is defined as "The cessation of life, the ceasing to exist; defined by the physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions consequent thereupon, respiration and pulsation". As developments in areas such as suspended animation, whereby organs were maintained after they had been removed from the dead body [Pernick, 1988], and resuscitation, by which previously fatal head injury patients were sustained and supported by mechanical devices such as respiratory ventilators [Lock, 2002] progressed, questions about the moment of death began to be posed.

In response to such questions formal debates about the need for a new definition of death that was brain-based commenced and resulted in the present day criteria of 'brain stem death' in the UK and 'whole brain death' in the USA. Influential to these debates was the argument that patients sustained on ventilators were a valuable source of viable organs for transplantation. However, without a fixed time point of death, doctors were concerned that they were at risk of being accused of killing those patients from whom they removed organs such as the heart or kidneys [Tilney, 2003].

Professional and public concerns

Although the guidelines for diagnosing brain death have been in existence since the mid 1970s in the UK and late 1960s in the USA, diagnosing brain death has not reached a stage of universal agreement between health professionals. Debates polarise around whether the criteria available to diagnose brain death [whole brain or brain stem] are biologically plausible [Potts and Evans, 2005], are consistent with present legal approaches to the diagnosis of death [Kerridge, 2005], and whether the diagnosis of brain death corresponds to any coherent philosophical understanding of death [Truog and Robertson, 2003; Jones, 2000]. This lack of agreement between health professionals is reflected to some extent by the public, who are reported to have concerns and a lack of knowledge regarding this diagnosis [Franz et al, 1997; Pearson et al, 1995; Siminoff et al, 2001, 2003, 2004].

Public concern has been clearly articulated in countries such as Denmark and Japan [Rix, 1999; Lock, 1999, 2002] where public views have been responsible for delaying intended legislation confirming the diagnosis of brain death. For example in Japan debates have continued since the first heart transplant carried out there in 1968, after which the surgeon was accused of “illegal human experimentation”, and of exercising “dubious judgement in relation to the donor’s death” [Bowman and Shawn, 2003:212]. Following many Bills to legitimise the diagnosis of brain death, all of which were opposed by the majority of the public [Bowman and Shawn, 2004], Japan passed a Bill in 1999, 31 years after the first transplant from a brain-dead donor.

A different kind of death

The potential organ donor has, usually, suffered an unexpected catastrophic brain injury that has resulted in the death of the brain stem. Patients who die in such a way are considered by the medical professions to be potential organ donors, and therefore will undergo specific testing to confirm death. The medical professional will make a request to the nominated or ‘qualifying person’, who is usually the next of kin, requesting their ‘appropriate consent’ for the organs and tissues of their deceased relative to be used in transplant operations [Human Tissue Act, 2004]. Due to the technical nature of brain stem death, testing and diagnosis, usually takes place in an Intensive Care Unit [ICU], where death is more usually, sudden, or as a result of a staged withdrawal of treatment.

The literature around the social organisation of death Harvey [1997] suggests that the strategic practice of withdrawing technological support from the dying patient in stages, aims to mimic the more gradual decline of natural death. This ‘technological regulation of death’ has two purposes: i] it allows both the family and health care professionals time to adjust ‘emotionally’ to the patient’s imminent death, and, ii] it allows death to be presented in a less dramatic fashion [Harvey, 1997: 719]. The procedure for this strategic withdrawal is that health care professionals aim to communicate a ‘death trajectory’ [Glaser and Strauss, 1968] by using ‘pessimistic communications’ [Seymour, 2001] regarding the seriousness of the critical injury, followed by communication of a deterioration in the patient’s condition or failure to respond to treatment. There is usually the demarcation of a time-line within which, if no change takes place, this lack of change will be interpreted as prognostic of the futility of ongoing intervention. A discussion about withdrawing treatment will take place, and if agreed, drugs will be gradually reduced so as not to precipitate a sudden death,

interventions will be minimised and equipment removed. Frequently family members are left alone with the patient and time is allowed for extended family or important others to gather at the bedside. As Harvey [1997] states “the withdrawal of technological support renders the process of ‘death’ very visible” [p: 725].

This is not the situation when organ donation is to take place. There are subtle but specific differences in the format of the regulation of death. Health professionals communicate a death trajectory using pessimistic communications regarding the seriousness of the critical injury, but interventions are then increased, for example drugs are increased in an effort to maximise the quality of the potential organs for transplant operations, personnel are augmented with the addition of the transplant coordinator, and discussions take place regarding the time that the deceased will go to the operating theatre for donation to take place. The potential organ donor is not left alone with their family for extended periods of time as any change in their status must be dealt with immediately to maintain the quality of the potentially transplantable organs.

Therefore unlike the ‘usual’ death facilitated within the ICU potential organ donors are not treated as though they are dead. What, if any, impact such contradictions may have on the experiences of the family members of potential organ donors was the stimulus for this study, which aimed to explore the concept of brain stem death by asking: i) What does the diagnosis of death based on brain stem testing mean to bereaved family members who have been approached and asked to consider donation from a deceased relative? and ii) How do family members understand the concept of brain stem death?

Method

To address these research questions a secondary analysis of two primary datasets was conducted applying techniques from Charmaz’s [2000] constructionist grounded theory method. Secondary analysis was used in this research as it has been shown to be beneficial in studies where: the issues to be addressed are of a sensitive nature, where studies are difficult to repeat, or where the relevant research population may be elusive [Fielding, 2004], which was the case in this research. Two primary datasets were available for secondary analysis and these were:

Dataset 1 *Organ and tissue donation: Exploring the needs of families.*

[Sque, M. Long, T. and Payne, S. February 2003].

The aims of the study were to:

1. Identify the impact of initial care offered to relatives in terms of decision-making about donation and subsequent grief.
2. Identify ways of enabling relatives to make choices about organ and tissue donation that were right for them.
3. Assess the need for bereavement support and the effectiveness of any support received.
4. Compare the process of bereavement for relatives who agree to donation, and those who decline.

This three-year study investigated the experience of bereaved adults with whom organ and tissue donation was discussed and who either agreed to donation [n = 46] or declined donation [n = 3]. Face-to-face sequential interviews were carried out at three time points 3-5 months, 13-15 months and 15-26 months post bereavement for donating participants, and single interviews at approximately 13 months post bereavement for non-donating participants.

Data collection took place between February 2001 and August 2002. The data from this study was available as 131 audio-recorded interviews as well as the transcribed text of these interviews. The field notes and researchers' notes were also available. A thematic analysis of the interview data collected was carried out. The first author [TL] was employed as the research fellow for this study and was responsible for the day to day implementation of the research for example: agreeing recruitment procedures, contacting potential participants, arranging interviews, carrying out all data collection, preparing interim advisory team reports, co-analysis of data, and co-authorship of the final report.

Dataset 2 *The Experience of donor relatives, and nurses' attitudes, knowledge and behaviour regarding cadaveric donotransplantation.* [Sque M. 1996].

The aims of this study were to:

1. Examine relatives' emotional reaction to the death of a family member and donation of their organs.
2. Elicit their perceptions of their decision-making process

3. Assess the benefits and problems that organ donation may have generated for them
4. Gain an understanding of what the experience of organ donation meant to them and to identify their needs.
5. Provide a substantive theory to explain donor relatives' experiences.

Sque's study investigated the experiences of 24 relatives from 16 families who experienced the death of a family member and who had agreed to organ donation. The study also elicited the attitudes, knowledge and behaviour of registered nurses within the UK with regard to organ donation. The data relating to the attitudes, knowledge and behaviour of nurses was not included in the secondary analysis.

The study was cross-sectional as data was collected between March and September 1994 via single face-to-face interviews. Data analysis was carried out using a grounded theory approach [Strauss and Corbin, 1990]. Data from this study was available as 16 transcribed texts and five audio recordings of interviews. The researcher's field notes were also available. The first author [TL] was not involved in this study and access to this data was granted by Sque.

Access to two datasets potentially offered many perspectives of an event that the person whom the deceased would expect to make decisions on their behalf had experienced. All family members had participated in a discussion whereby their relative was pronounced dead after brain stem testing. The outcome of this diagnosis was to then approach the family and ask them to consider donating the organs and/or tissues of their deceased family member.

Sorting the primary data

Whilst some authors who carry out secondary analyses re-analyse a complete primary dataset, it is more usual that some form of 'sorting' [Heaton, 2004: 59] of data takes place. Sorting may be applied for different reasons i.e. sorting to: separate quantitative data from qualitative data [Clayton et al, 1999], interview data from observational data [West and Oldfather, 1995], to focus on one type of data, to identify a sub-sample of the primary participant population [Kearney et al, 1994] or so that analysis can be selectively limited to specific themes or topics [Gallo and Knafel, 1998]. The latter is the case in this study.

One hundred and forty-seven interviews were reviewed for inclusion in the secondary analysis. The inclusion criteria were based on: the fit between the primary data and the secondary research questions, a fit between the primary and secondary research methods, and that the data offered appropriate depth and detail [Hinds et al, 1997] in relation to the substantive area of interest. Each transcript was assessed for depth and detail in that data provided some coherent discussion of what brain stem death meant to family members, what their reactions to, and their views, knowledge, beliefs and/or understanding was, regarding the diagnosis of death based on brain stem testing.

Family members

Twenty-eight interview transcripts were finally sorted from the primary datasets 22 from Dataset 1 and six from Dataset 2. The final dataset available for secondary analysis consisted of: 18 first interviews, 7 second interviews, and 3 third interviews [Table 1]. The 28 transcripts represented interviews carried out with 22 family members, 13 family members from Dataset 1 and nine from Dataset 2. Their relationship to the deceased was: six sets of parents, two fathers, two mothers, three husbands, and three wives. Parents had experienced the death of a child, adolescent, or young adult whose age ranged from 11-34 years. The cause of death in these cases was predominantly brain haemorrhage and injuries sustained in road traffic accidents [one child died after developing meningitis]. The age range of the spouses or partners who died was 42 – 57 years, and the cause of death was some form of brain haemorrhage. All of the deceased relatives had been well and involved in usual daily activities up until the critical illness or injury.

Table 1 . Demographic data for participating families

Dataset	First or single interviews	Second interviews	Third interviews
Dataset 1	12	7	3
Dataset 2	6		
Total	18	7	3

Ethical considerations

There are ethical considerations when carrying out any research, but there are specific considerations related to secondary analysis of primary datasets. Heaton [1998] comments that informed consent cannot be presumed in secondary analysis, and that the researcher

cannot rely on the vagueness of the initial consent form [Thorne, 1998]. The South East Thames Multi Research Ethics Committee [MREC] who approved primary study 1 were consulted and agreed that a secondary analysis could be undertaken. Ethical approval for primary study 2 had been gained from the University Ethics Committee, and the Medical Director for the Transplant Co-ordination service that facilitated recruitment. Family members in the study had given consent that the interview data could be used for secondary analysis, and therefore this was judged to be sufficient agreement for use of the primary data.

Data analysis

Preliminary analysis

The 28-sorted transcripts were edited and imported into Atlas ti version 5, a qualitative software programme, in preparation for preliminary analysis, initial coding and memoing. The 'raw data' [Heaton, 2004] of the 28-sorted transcripts were re-coded [no codes were used from the primary analysis]. This meant that a new coding list could be generated and expanded as analysis proceeded. Preliminary analysis consisted of reading the 28-sorted transcripts and noting initial themes relating to how family members articulated their experiences of receiving a diagnosis of brain stem death.

Initial coding and memoing guided theoretical sampling, a technique whereby the researcher makes active decisions as to where to look for more data to clarify, expand, or condense initial themes to develop categories. Ideas about the developing categories, their properties and dimensions, and possible relationships between them were recorded in memos. Three categories were developed: *conflict*, *communication* and *rationalisation* which all relate to the basic social psychological process [Glaser, 1978] of *Conflict Rationalisation* which was identified as the key category [Charmaz, 2006]. *Conflict Rationalisation* is a process whereby participants [as next of kin] and health professionals engage in a series of practical and psychological activities aimed at rationalising real or potential emotional and cognitive conflict resulting from a diagnosis of death, which is brain-based, whilst being faced with the physical image of a functioning body. Rationalising emotional and cognitive conflict is how participants and health professionals appeared to process this paradoxical death, a death that is contrary to received, conventional opinion. This process is explained as the Theory of Paradoxical Death [Long, 2007].

Findings and discussion

As is usual in grounded theory the findings are presented in combination with the discussion and for clarity in the form of three integrated propositions: 1) Paradoxical communication and the environment of the ICU contribute to emotional and cognitive conflict. 2) The technology of life support contradicts the diagnosis of brain stem death. 3) Family members and health care professionals seek to rationalise the emotional and cognitive conflict stimulated by the diagnosis of brain stem death.

1. Paradoxical communications and the environment of the ICU contribute to emotional and cognitive conflict.

Analysis indicated that initial communications by health professionals were aimed at informing family members about the potential consequences of the critical injury sustained by their relative. These 'illness related' communications, which were prompted by the nature of the critical illness, were interlinked with 'priming communications', and 'confirming communications', which were death related. Staged information of poor progress, no response to treatment, sudden changes in condition along with specific language appeared to be used by health professionals as preparatory communications. For example family members were in receipt of the following forms of communications:

Informing communications such as:

"They told us as soon as he went in there [hospital] [that] because of the amount of time he was probably dead he would probably be in some shape, form or size brain damaged. But we didn't know until they had carried out certain tests and standards and put this monitor inside his head just how badly the brain damage was because his brain was very swollen, there was a lot of swelling inside. They did say to us about they don't know whether, you know, whether the swelling would go down and everything. It did go down a little bit I think someone said, but the damage that happened was that the main part at the front of his head so that is obviously why they couldn't get no reaction, when, you know they took out the knock out drops." [stopped sedative drugs] [Participant No. 13]

Informing and priming communication:

"The conclusion they found from the angiogram was they found a weakness in blood vessels and a small bleed in the right side of the brain, explaining cause of slight weakness in the left hand side. They found a cyst in the centre of the brain, not connected to this original haemorrhage, which is on the left side of the brain. A second bleed, which took place on Wednesday, also on the left hand side, speech was slurred and may, speech may be slurred and was affected by the second bleed.

He also told us on that occasion that [J] was a very, very sick man and he came, quite right, that [J] was dying most, that a strong possibility, no, that [J] most probably would die." [Participant No. 10]

Priming communication:

"In fact the doctor said if he by any chance comes through this he's going to be so severely brain damaged you won't know him and he won't know you. At that stage I didn't know what to pray for whether I wanted him to live or I wanted him to die." [Participant No. 5].

In the above example the possibility of brain damage is introduced. The term 'brain damage' was a regular feature of priming communications and as shown in the above example contributed to conflict, as this mother did not know whether to pray for life or death. 'Brain damage' may be used to prime the diagnosis of brain stem death because the image of a brain-damaged individual has particular schema generating qualities. This schema may result from media programmes that portray images of brain-damaged individuals, or personal preconceptions such as the view of those with brain damage being a 'vegetable'.

"And I remember just praying that he wouldn't become a vegetable and praying that he would die, but that was hard because you are praying for your son to die and of course you don't want him to die. I had looked after patients who had been vegetables for years and I couldn't bear to think of him like that and just to have P and not be a vegetable was really important to me." [Participant No. 3]

If the idea of brain damage was of particular concern for the family member the potential for it increased emotional and cognitive conflict as the risk of surviving with brain damage appeared to be of greater concern to some family members than the fear of death itself. Jones [1999] suggests that brain stem death may be thought of as death "because it signals the irreversible end of mental life" [Jones, 1999]. It may be that for some individuals the diagnosis of brain death and the link to brain damage represents the irreversible loss of mental life but not actual death, which is signalled by the cessation of heartbeat and respiration. The paradox of the communication of death in the face of continuing heartbeat and respiration appeared to be the trigger for emotional and cognitive conflict as family members dealt with the two mutually exclusive outcomes being communicated to them; potential life with brain damage, or potential death.

According to Bogdan [1982] a “paradox depends upon the existence of a hierarchy of messages such that one message comments on or qualifies another” [Bogdan, 1982:443]. Therefore when two messages seem to comment on each other in contradictory ways the result is what Ruesch and Bateson [1951] refer to as paradoxical communication. Bogdan [1982] explains that messages and metamessage can flow from speech or nonverbal behaviour, or from behaviour and from “the context within which it takes place” [Bogdan, 1982:443]. Therefore the paradox is that family members receive the metamessage of life enhancement in the face of a functioning body and the message that death has occurred.

A further consideration is that the communication of potential brain damage may reflect unease within the health professionals who diagnose death based on brain criteria. The extant literature indicates that there is an ongoing debate within medicine about the diagnosis of brain death:

“At a practical level, [the concept of brain death] has been successful in delineating widely accepted ethical and legal boundaries for the procurement of vital organs for transplantation. Despite this success, however, there have been permanent concerns over whether the concept is theoretically coherent and internally consistent; indeed, some have concluded that the concept is fundamentally flawed and that it represents only a superficial and fragile consensus.” [Truog, 1997].

More specifically authors such as Youngner et al [1985, 1989] and Sundin-Huard and Fahy [2004] have reported that doctors and nurses believe that brain dead patients are ‘irreversibly dead’ or have an unacceptable quality of life rather than being actually dead. Kaufman [2005] suggests that physicians use phrases such as quality of life ‘deliberately’ with the aim of ‘affecting’ how family members and other health professionals construct meaning in relation to patients’ experiences and to ‘justify action’ [p:209]. Phrases such as: ‘If kept on the respirator the patient will die of sepsis’ or: ‘at this point in time it doesn’t look as if the patient is going to survive’ [Kerridge et al, 2005: 91], are used it would appear, to reassure family members that the patients will die no matter what - not that they are dead. Kaufman [2005] goes on to say that physicians adopt such phrases as a means of rationalising “complex feelings that doctors may find difficult to consider or express” [Kaufman, 2005: 209].

2. The technology of life support contradicts the diagnosis of brain stem death.

Seymour [1999: 691] suggests that it is the “perception of the meaning of technology” that influences how death is represented in ICU. Analysis suggested that whilst technology was initially seen as beneficial, and in fact had saved the life of their relative, there came a point in time for some family members when technology was perceived to be not in the best interests of the critically injured individual.

“I couldn’t see [A] laying in the bed in that condition, being artificially kept alive, although I no longer believed he was alive. I just believed that his body was functioning and so I wanted to see him released from that. I wanted to see him given the chance to prove one way or the other, with the least discomfort.” [Participant No. 12]

This quote gives an example of the contradiction that existed for some family members as they ‘believed’ their relative to be dead, but still saw them as alive and being able to ‘prove’ that they were dead or alive, as though there was still some ability to determine their future. It appears that technological ‘life support’ equipment “obscures impending death even when there have been repeated warning and explanations about the likely outcome of an illness” [Seymour, 2001:70].

Despite family members receiving warnings and explanations, terminology such as ‘being kept alive on the ventilator’, and ‘life support’ may have undermined the message that death was inevitable. Franz et al [1997] goes so far as to say that the term life-support should not be adopted when caring for the brain dead patient due to the possibility of confusion regarding death. The term ‘brain stem death’ may itself suggest that death certified by testing is inclusive to the brain and exclusive of the body. This choice of language may undermine the acceptance of the irreversibility of the brain injury sustained and may support the view that the relative could recover with intensive rehabilitation.

Analysis suggested that the impact of technology was amplified by family members’ schema of a dead body, which was based on signs such as no breathing, no heartbeat, no movement and a lack of colour:

“The thing is, when you see someone on a ventilator, even though they say they are brain dead, they are still breathing, they are still warm, they still look good, they don’t look dead. To me M was, I mean, the colour, he was so tanned, so he didn’t go white really, but he had so many bad

infections that he had a high colour because he had, obviously, a temperature. So he never, ever, all the time that week, he didn't look like he was dead at all. I suppose we felt like he was still alive, you know what I mean, even though we were donating his organs, because he looked alive, he did, he looked really good you know. He just looked so good, they all kept on saying that, you know, the nurses, he looked so good, it was a complete waste of life." [Participant No. 16]

The diagnosis of 'brain stem death' was in conflict with the body in question, as the diagnosis did not agree with the schema of a dead body. Whilst there may be debate about a schema of a dead body, a characteristic that is agreed upon by the analysed incidents is that a dead body does not breathe and is cold and motionless. The fact that family members continued to see a body whose chest rose and fell as in breathing, and who was warm to touch, whilst being diagnosed as dead appeared to trigger emotional and cognitive conflict which may only be resolved when the body is congruent with the schema of a dead body:

"When we saw him in the mortuary we saw death itself which was a contrast. It was a stark contrast to what we had seen, or what I had seen in the brain stem test situation. He was cold, motionless it was a shock."
[Participant No. 4]

Rix [1990] suggests that the identity of a person comprises of the 'integrality' of consciousness and body, but that as identity relates as much to the mind as to the body, death cannot be said to have happened while heartbeat and breathing continue. A body in this situation "cannot be referred to as a corpse" [Rix, 1990: 6], although from a medical perspective it would. Respiration, heartbeat, warmth and "normal colours" [sic] [Rix, 1990, p 6] signify that life has not ended, and therefore death diagnosed by brain stem testing constitutes a paradoxical death.

3. Family members and health care professionals seek to rationalise the emotional and cognitive conflict stimulated by the diagnosis of brain stem death.

Analysis and the extant literature support the views that family members and health professionals experience emotional and cognitive conflict in relation to the diagnosis of brain stem death. In the case of family members, the conflict is as a result of the way the body looks, which is counter to their perceived expectation of a dead body, and is reinforced by the paradoxical communications of health care professionals. In the case of health care professionals, who may be uncomfortable with this diagnosis; the conflict is between

intellect and emotion. Fundamentally this conflict is linked to the 'primordial anxiety' that is generated by our concerns in relation to death [Yalom, 1980].

Mills [1989], states that the most common responses to death and dying in our society are those of 'anxiety and avoidance'. Yalom [1980] also comments that "death whirs continuously beneath the membrane of life and exerts a vast influence upon experience and conduct" [p: 29,] and that due to the effectiveness of our denial of death [a defence mechanism] it is only when 'a boundary situation': an event or urgent experience which propels us into a confrontation with our 'existential situation' in the world, occurs, and that we cannot avoid, is death anxiety provoked. An example of a boundary situation may be the experience of the diagnosis of brain stem death! Yalom goes on to say that death anxiety is handled by protective mechanisms that are learned or developed such as: "repression, displacement and rationalisation" [p: 45].

Rationalisation is one of a number of what were referred to as defence mechanisms, and are now referred to as coping strategies [Freud, 1937; Stanescu and Morosanu, 2005]. Defence mechanisms are employed when an individual perceives a conflict situation and needs to reduce the resulting anxiety. Defining rationalisation as: the process through which things that were confusing, obscure or irrational are made clear [Reber, 1985], the argument is that the diagnosis of death in the face of a live looking body is irrational; that the communication of uncertain death, but definite brain damage, is confusing, and that both the fact and use of life support equipment obscures death. So how do families deal with this obscured, irrational, confusing situation?

Rationalisation of conflict and anxiety appeared to be achieved by family members: focussing on the possibility of a damaged survivor and what this might mean to the 'nearly dead' or 'actually dead' relative, choosing to view brain stem testing, the articulation of a moment of death prior to brain stem testing, and seeking meaning in what has been described as a complete waste of life. Focussing on the possibility of a damaged survivor was linked to the need for an undamaged survivor; either because this was what the potentially deceased relative has said in life, or, because it was important to the bereaved family member. The fact that a damaged life was not acceptable to the deceased or to themselves was a stimulus that triggered coping strategies such as rationalisation.

“ and [J] had always said the one thing she couldn’t stand the thought of having brain damage or having a stroke or anything she wouldn’t want to live like that in a wheel chair or disabled or dribbling that wasn’t her scene at all.” [Participant No. 8]

Rationalisation was a coping strategy that appeared to be helpful to family members both immediately and over time. The longitudinal data available in Dataset 1 indicates that family members focussed on brain damage as ‘a fate worse than death’, as a way of rationalising the death of their relative.

“He was going to be severely brain damaged, it’s better that it happened as it did. I’ve got my ex-boss who has a son who is severely brain damaged and its been five or six years now, its just. I mean he was a little older than [M] but fit, into everything, again to see him now, it just hurts me to see him and I... You know sometimes I think well thank you, but [M] had to go and he didn’t get left half you half and half, which could have happened. I don’t know, I don’t know enough about it. I’ve not questioned that, I’ve not delved into what I know what happened and I don’t you know that is, it’s happened, won’t bring him back so there is no point in delving into that really.” [Participant No. 2].

Some family members wanted to observe brain stem testing during which they saw their relative unable to breathe. As the absence of breathing is an agreed sign of death, this was a potent indicator that their relative had died.

The articulation of a moment of death indicated a point in time whereby family members perceived that the critically injured patient had moved from a recovery trajectory to a dying trajectory [Glaser and Strauss, 1968]; a point in time that marked a transition. The transition point for family members to move from a recovery trajectory to a dying trajectory was usually a set of indicators that may be: practical, emotional, cognitive, spiritual or a combination of the aforementioned. On some level a change had occurred that was a ‘demarcation of death’, an indicator that their relative had ceased to be alive.

“Because there was no reaction whatsoever. Erm, there was originally, for a second I thought there was a reaction and I thought she may not be unconscious, but maybe just, erm, my guess she’s unconscious. Erm, I was thinking of, like a stroke, that you’re physically incapable of carrying out certain things Erm, so I was trying to squeeze her hand, tried to talk to her, see if I could get anything, but I then looked at her eyes. And that’s what made me decide, and, and the fact that, like, she was always very pale to start with. Erm, but the fact that there was completely cold fish eyes, she was, she had no life, no sparkle in her

eyes, and having seen that, that's what made me, erm, think that she was dead." [Participant No. 15].

This demarcation of death was linked to a change in the emotional connection between the family member and the deceased, and appeared to move the next of kin into a dying trajectory mode of thinking. This mode of thinking indicated that whilst family members mark the moment of death by the cessation of breathing and heartbeat, they also recognise the process of death, and that when the brain function has ceased the person has entered a death process, a process of no return. There appeared to be a subtle difference in meaning here between family members and health care professionals. Analysis suggested that for family members the cessation of brain function marks the moment that the critically injured person enters the death process, whereas for the health professionals, it marked the end of the death process.

This difference in view regarding how death proceeds for the organ donor may underpin the concerns raised in the literature and the uncertainties articulated in this study regarding the diagnosis of death in the face of live looking body. Both the context and environment in which this death takes place contributes to a paradoxical death. The context is one of sudden death with the patient being a potential organ donor and the environment is that of the ICU, an environment bristling with technology and action which supports an image of 'medical surveillance and control' whilst articulating 'uncertainty' [Harvey, 1996:90]. In relation to brain stem death this uncertainty is articulated by health professionals in their style of communication about this particular diagnosis, a diagnosis which Harvey [1997], referring to brain death, suggests is 'perhaps the ultimate technological death' and that as such it presents particular challenges to physicians who must communicate death to family members [p: 729]. The challenge is that whilst communicating death, the patient does not fulfil "the 'normal' criteria of death which are: 'no heartbeat, cessation of breathing and complexion turning blue' [Harvey, 1997:729] and therefore the family member is faced with a paradox which triggers the process of '*Conflict Rationalisation*' whereby family members and health professionals engage in a series of practical and psychological activities aimed at rationalising real or potential emotional and cognitive conflict resulting from a diagnosis of death which is brain based whilst being faced with the physical image of a functioning body.

Secondary analysis

Applying a secondary analysis has fulfilled the aims of: i) addressing a sensitive area of research, ii) accessing a research population that may be 'elusive' [Fielding, 2004], and iii) has facilitated the application of research questions, which whilst being linked to the substantive area of the primary research explored different issues. Data collection, in the form of sorting transcripts that had enough detail about the experience of being involved in the diagnosis of brain stem death, generated data that was sufficient to successfully carry out this initial exploration of what this diagnosis meant to family members. Secondary analysis is another tool that the researcher can adopt to, as Glaser [1963] puts it "lend new strength to the body of fundamental social knowledge" [Glaser 1963: 11], and although not the case in this study offers a way in which those people who wish, or need to, carry out research, but who are employed in areas that exclude them from individual data collection i.e. teachers and students can carry out empirical research.

Limitations to the study

The secondary participant data accessed for this study was gathered from a specific population. That population was those family members who had been in receipt of a diagnosis of brain death in relation to a relative, and who had agreed for the organs of their relative to be donated and used in transplant operations [data from non donating family members did not meet the sorting criteria for secondary analysis] therefore the findings are limited to those individuals who agreed to organ donation. Further research involving families who decline organ donation would address the question of whether the key category from the theory of Paradoxical Death, that of *Conflict Rationalisation* is pertinent to this population also.

A weakness of the study was that the views of health professionals regarding the diagnosis of brain stem death were gained from contemporary literature, and not directly from health professionals. This is an important topic to address in future research as new initiatives are proposed impacting on the diagnosis of death and the role of health professionals and family members within it [Academy of Medical Royal Colleges, 2006].

Conclusion

How individuals perceive death to have occurred is a fundamental issue in organ donation, and this work has indicated that their perception is not always congruent with medico-legal

definitions of death. The diagnosis of brain death is a difficult issue due in part to the questions that it raises about life and death: What is death? When does it happen? And does life linger on after a diagnosis of brain death? But also, in part, to reported poor knowledge levels of family members and paradoxical communications by health care professionals. Nurses and doctors may experience moral conflict when caring for the patient diagnosed as brain dead as by removing organs “we have challenged deeply held fears about medical science and the proper treatment of dead bodies” [Youngner, 1990:1015]. This ‘dark side’ of organ transplantation is confronted by health care professionals but not presented to the public. Maintaining organs for transplantation necessitates treating dead people in many respects as if they were alive and that while health care professionals may accept this on an intellectual level they may find it difficult “to ignore the signs of life that constantly bombard their senses as they provide the brain dead organ donors with intensive and intimate medical care” [Youngner et al, 1985:321], care that is in direct opposition to what one would normally provide for a dead patient. It is interesting that despite these reported moral conflicts and low knowledge base the House of Lords Select Committee on Medical Ethics reported that; “both medical and lay opinion have evolved to a point where there is now almost total acceptance of a single definition of brain stem death and widespread understanding of its implications and management” [House of Lords, 1994: 53]. This work would question the certainty of this statement.

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