The experience of ambiguous loss in families of brain injured ICU patients

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ABSTRACT

Background: Advances in medical technology have led to increased survival rates for critically ill patients, resulting in the survival of patients with serious traumatic brain injury. These patients may suffer some permanent brain damage leading to an ambiguous loss in families. Ambiguous loss has two dimensions: (1) a loss that relates to the physical absence but psychological presence of the family member and (2) a loss that refers to the psychological absence but physical presence of the family member.

Aim: The overall study aimed at exploring families’ experiences with critical illness in intensive care and nurses’ perception of families. This article presents findings of one specific aspect, namely, families who experienced an ambiguous loss following the patient’s brain injury which resulted in permanent brain damage.

Design and method: Constructivist grounded theory that used focus groups as the method of choice. Reported data originate from nine family interviews (12 adults, 12 children/young people).

Data analysis: Interviews were recorded, transcribed verbatim and imported into NVivo for data management and analysis. The principle approach in grounded theory, the constant comparative method, was followed.

Results: The findings suggest that ‘the emergence of ambiguous loss’ reflects the families’ experiences with the second type of ambiguous loss, namely a loss that relates to a family member who was physically present but psychologically absent. ‘Mapping the future’ is a further dimension of this theme which underlines the impact of an ambiguous loss on everyday family life.

Conclusion: Families where the patient had suffered permanent brain damage experience an ambiguous loss. In this situation a caring scenario emerged which had a fundamental impact on the family’s future. The dimension of ‘mapping the future’ draws out these implications for different family members.

Relevance to clinical practice: Nurses need to be aware of the implications an ambiguous loss can have on families.

Key words: Family care in critical care • Family-centred care • Family nursing • Interview/focus group techniques • Qualitative research

INTRODUCTION

The intensive care unit (ICU) of today, from the neonatal ICU to the adult ICU, stand as ‘a monument to science and technology, a living testament to the vast resources that our society has committed to saving life’ (Anspach, 1997, p. 1). The modern medical technology in ICUs is, as Chesla (1996) points out, directed towards the ‘moment-by-moment’ management of physiological changes and needs of critically ill patients. For families, entering an ICU during their family member’s acute critical illness, it can be difficult to distinguish between the purpose of the technology and the expectations and hopes the use of this technology triggers in relation to their family member’s survival and recovery. Zussman (1994) makes the astute observation that ‘intensive care’ is actually a place and not a technology: a place whose purpose is to manage medical crises with technological support for failing organ systems. The use of technology to manage physiological crises is by no means indicative of any long-term outcome.

This viewpoint is reflected in the fact that survival, as such, is understood as an ICU outcome measure in which advances in pharmacology and technology play a significant role in improved survival rates (Keenan and Dodek, 2004). What survival figures do not convey is the state in which a patient survived a critical illness or a lifesaving intervention such as
cardiopulmonary resuscitation (Timmermans, 1999). The human costs are not always clear at the beginning of an intensive care treatment nor can they be. The patient’s acute condition forces a physician to act on what is known at the time of a lifesaving intervention (Bosk, 1979/2003).

For families, however, the fact that the patient was admitted to ICU might well imply that their family member has a good chance of survival and, therefore, recovery. In the case of ICU patients who have suffered a traumatic brain injury (TBI), recovery is surrounded by a considerable amount of uncertainty. It is not a new insight that the long-term impact of TBI goes beyond the patient and extends to the family (Cavallaro and Kay, 2005; Landau and Hissett, 2008; Lefebvre et al., 2008), in particular when the outcome is survival with some degree of permanent brain damage. In those cases where patients have suffered permanent brain damage, the end of the initial life-threatening crisis does not signify the end of an illness for patients and families but rather coming to terms with a loss that has no final resolution (Williams, 1991; Montgomery et al., 2002).

Ambiguous loss
It appears that the term ‘ambiguous loss’ was first used in the North American literature by Pauline Boss, a family therapist. ‘Ambiguous loss’ is a term that refers to the ambiguity, the ‘unfinishedness’ of a loss that has occurred.

Ambiguous loss is an under-researched aspect of loss and, only a few, diverse examples exist within the research literature. Children, who have gone missing and where families do not know what has happened is one example (Lewis-Fravel and Boss, 1992; DeYoung and Buzzi, 2003). Soldiers missing in action or missing family members after the terrorist attacks of 9/11 are further examples of ambiguous losses (Boss, 2002a, 2002b). A more everyday life example might be a family situation postdivorce where a parent or a child is physically absent but psychologically present (Boss, 1999).

Conceptually, there are two different types of ambiguous losses. In the first case, ambiguous loss refers to a person who is physically absent but psychologically present in the family. The above-mentioned scenarios are examples of this type of loss.

The second form of ambiguous loss relates to a family member who is physically present but psychologically absent (i.e. after brain injury, Alzheimer patients, some mental illnesses). Jones (2002), using the grief process as framework in a phenomenological study investigating the impact of mental illness on families, provides such an example. The ambiguity of the loss was evident when families described their time of loss as a ‘marked discontinuity in the behaviour and being’ while their ill family member was portrayed as ‘being separate from the true self’ they used to be (Jones, 2002, p. 37, 40). It is this type of loss, where the family member is physically present but psychologically absent, that is of interest where a family member has suffered a TBI which resulted in permanent brain damage.

This article draws on selected findings of a constructivist grounded theory study. Data are based on family group interviews and relate to families’ experience of an ambiguous loss following their family members’ brain injury.

‘Family’ for the purpose of this study was defined as a group of persons who share a history and a future and are committed to each other. Individuals define themselves as part of that particular family (Kean, 2008, p. 98). This viewpoint acknowledges that there is no agreed definition of what constitutes a family in today’s society (Gubrium and Holstein, 1990; Bernardes, 1997; Greenstein, 2006).

THE STUDY
Aim
The study explored families’ experiences with critical illness in ICU and nurses’ perceptions of families (Kean, 2008). This article presents findings of one specific aspect, namely, families who experienced an ambiguous loss following the patient’s brain injury which resulted in permanent brain damage.

Design
This study was organized into two phases (1) family group interviews and (2) focus groups with nurses and followed a constructivist grounded theory approach (Charmaz, 1990, 2006). Only data from family group interviews are presented here.

It was assumed that no one single family member could verbalise the experiences of critical illness for the whole family and therefore a ‘family as unit’ approach was chosen. The implications of a systems perspective, which focuses on processes within families, allowing the research to capture diverse family forms, changes to family composition and characteristics over time have been discussed elsewhere in more detail (Kean, 2009). Here it is sufficient to say that family systems data are constructivist in nature and do not result in a family experience but rather represent the different realities of individuals in groups. It is the processes by which families not only share realities, but also maintain and construct their separate realities (Hess and Handel, 1959/1995), within their interdependent and independent lives that are of interest in examining family experiences with critical
illness. This epistemological stance provided the rationale for doing group interviews.

**Sampling**
Grounded theory employs theoretical sampling, which involves the strategies of simultaneous collection and analysis of data (Glaser and Strauss, 1967; Glaser, 1978). Sampling at the beginning of a study is general and open and becomes focussed as the theory develops. Through coding, comparative analysis and memo writing, gaps in the data are identified and directed sampling filling in these gaps. This process is described by Charmaz (2002) as a self-correcting step. The researcher followed Charmaz’s (1990, 2000) recommendation using theoretical sampling at a later stage in the research process, after key themes had emerged.

**Data analysis**
All interviews were recorded, transcribed verbatim and saved in rich text format. The principle approach to data analysis in grounded theory, the constant comparative method (Glaser and Strauss, 1967), was followed. Data analysis started with the first interview and moved from open to focussed coding (Glaser, 1978; Charmaz, 2000) as the study progressed. Analysis was aided by the use of NVivo 2.0 software for storing, coding and retrieving qualitative data.

Family interviews followed the convention of focus groups. In focus group research, the focal point of analysis is the interaction of participants (Carey, 1994; Kitzinger, 1994; Morgan, 1997; Bloor et al., 2001). There are differences in coding between different grounded theory approaches. Glaser (1978) and Charmaz (2000) identified a two-step process, while Strauss and Corbin (1998) favoured a three-step coding scheme. This study adopts the Glaser (1978, 1992) and Charmaz (1990, 2000, 2006) approaches in seeking patterns and processes. Coding data and analysis moved forward and backward from the group to the individual perspective by constantly comparing incidences within and across groups. The full printout of transcripts and retrieved coded data formed the basis of regular readings of the data.

**Ethics**
Ethical approval was obtained from the Local Research Ethics Committee (LREC). Ethical issues arising from the inclusion of more than one family member include, e.g., the development of study information and consent forms. Little has been written about the development of these forms in the context of children and young people. Lindeke et al. (2000) point out that there are few guidelines that help researchers to design developmentally appropriate information and consent forms.

For this study, both information and consent forms were developed by the researcher, and then the usefulness, readability and ease of understanding were evaluated in a series of discussions with a non-clinical sample of children and young people. Participants in these discussion groups reflected the age ranges of children and young people I wished to recruit for the study. The final versions of the forms reflect the suggestions made regarding layout and word choices.

All participants received information leaflets describing the study. Written consent to be interviewed and recorded was obtained prior to interviews. Parents of children below the age of 16 signed an additional consent form after their children had consented to participate. Participants retained a copy of their signed consent form. Further issues arising from the inclusion of children in research have been discussed elsewhere (Kean, 2009).

**Study sample: families**
Twelve adults and 12 children from nine families participated. Families were identified by the nurse in charge of the ICU of a large teaching hospital in a major Scottish city before being invited by the researcher into the study. Families, who spoke English, had children and where one adult family member had spent at least 3 days in ICU but was stable at the time of recruitment were invited to participate. Families of dying or unstable patients were excluded. Distressed family members were not approached.

In six of the nine families the husband or father was the critically ill patient, whereas in three further families the adult son or brother was in ICU.

Families are referred to as F1, F2 and so on while ages of children are given in brackets. All names are pseudonyms. An overview of families who experienced an ambiguous loss following the patient’s brain injury is provided in Table 1.

**FINDINGS**
The core experiences of families in the overall study emerged around ‘clinical and functional uncertainty’ (Davis, 1963/1991, 1966). Clinical uncertainty refers to the unknown and unknowable aspects of critical illness whereas ‘functional uncertainty’ calls attention to the management of information disclosure as a communication strategy (Kean, 2008). Table 2 provides an overview of the study’s findings.

The experience of ambiguous loss is nestled within the main themes of clinical and functional uncertainty and only emerged in five out of the nine families, i.e. in families where the patient had suffered some...
degree of brain damage. The findings of these families suggest that ‘the emergence of ambiguous loss’ reflected families’ experiences with the second type of ambiguous loss, namely a loss that relates to a family member who was physically present but psychologically absent. ‘Mapping the future’ is a further dimension of this theme which underlined the impact of an ambiguous loss on everyday family life.

The emergence of ambiguous loss
The issue of an ambiguous loss emerged first in family 2, where Brian had suffered a hypoxic event at some point during his critical illness, resulting in brain damage. During the interview Beth, his wife, and their adult son Ross (25) discussed Brian’s brain damage in the context of medical advances. Beth compared the current state of knowledge about the brain, as medical staff had explained it to her, with advances in organ transplantation, arguing that ‘twenty years ago nobody did heart transplantations, whereas now it is routine.’ In the interview she expressed her belief, which appeared to be based on a biomedical perspective, that advances in brain research would answer the family’s most pressing question, namely that of the extent of recovery one might expect for patients like Brian. Ross, however, appeared to have a different understanding of the situation.

Beth: ‘What do you mean? What do you mean? It’s not the same as what? (higher pitch, anxious)’
Ross: ‘As these heart transplants or mapping DNA or anything like this.’
Beth: ‘Oh! You mean finding out?’
Ross: ‘I think there is a fundamental problem.’
Beth: ‘Oh, you just mean that people don’t know much about the brain and how it works, and-’
Ross: ‘What I mean, there is – I think, there’s a fundamental problem. Why do people still go to church? Why do people still believe there’s a soul? . . . ’
Beth: ‘. . . Yeh.’
Ross: ‘All they can do is tell you that there’s electrical activity and body functioning. It’s like he’s not really there- like, you know, the essence of who he is, is not there. And I don’t see how they’re going to be able to pin down the essence of what someone is, because that is clearly something, which does not fit in with the physical things. They may make great leaps in reality in short periods of time over- for ah, a lot of physical stuff, you know, even mapping human genomes and knowing all about the DNA and everything. Potentially they can ah, they

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**Table 1** Overview of families of brain injured patients

<table>
<thead>
<tr>
<th>Family</th>
<th>Family members</th>
<th>Patient (age)</th>
<th>Type of injury</th>
<th>Lengths of ICU stay at time of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Beth (56), Ross (25)</td>
<td>Brian (54)</td>
<td>Hypoxia</td>
<td>7 days</td>
</tr>
<tr>
<td>3</td>
<td>Julie (45), Fay (12), Mona (10), Phil (4)</td>
<td>Peter (63)</td>
<td>TBI, accident – fall</td>
<td>13 days</td>
</tr>
<tr>
<td>4</td>
<td>Susan (41), Clive (40), Carrie (18), Alan (13), Ben (7)</td>
<td>Jon (19)</td>
<td>TBI, RTA</td>
<td>3 weeks</td>
</tr>
<tr>
<td>5</td>
<td>Andrew (49), Linda (54), Shona (20)</td>
<td>Hamish (19)</td>
<td>TBI, accident – fall</td>
<td>3 weeks</td>
</tr>
<tr>
<td>8</td>
<td>Jeff (42), Fiona (40), Jody (15)</td>
<td>Kieran (17)</td>
<td>TBI, RTA</td>
<td>10 days</td>
</tr>
</tbody>
</table>

**Table 2** Overview of study findings

<table>
<thead>
<tr>
<th>Main themes</th>
<th>Dimensions</th>
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</thead>
<tbody>
<tr>
<td>Families’ experiences during critical illness</td>
<td>Emergence of clinical uncertainty in critical illness</td>
</tr>
<tr>
<td>Clinical uncertainty</td>
<td>Clinical uncertainty</td>
</tr>
<tr>
<td>Functional uncertainty</td>
<td>Functional uncertainty within nurse–family interactions and within family interactions</td>
</tr>
<tr>
<td></td>
<td>Ambiguous loss</td>
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<tr>
<td></td>
<td>Mapping the future</td>
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<tr>
<td>Children and young people’s experiences with critical illness</td>
<td>Adults’ power of controlling information</td>
</tr>
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<td></td>
<td>Keeping normality in life</td>
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<td></td>
<td>Young people’s strategies of accessing information</td>
</tr>
<tr>
<td></td>
<td>Children’s strategies of accessing information</td>
</tr>
<tr>
<td>Nurses’ experiences with families in ICU</td>
<td>One space – two worlds</td>
</tr>
<tr>
<td></td>
<td>Emotional labour</td>
</tr>
<tr>
<td></td>
<td>Negotiated order</td>
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<tr>
<td></td>
<td>Negotiated family care in ICU</td>
</tr>
</tbody>
</table>

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can genetically eradicate various diseases and, you know, even grow human beings, but again there’s a fundamental problem within growing human beings, they don’t know what the essence of that person is, because it’s like his body is there but it’s really hard to see that he is still there because you don’t get anything, you know, nothing comes forward.’

Beth: ‘Yeh. (reflective)’

Ross: ‘You can’t see that he’s there.’

Ross carefully proposed here to his mother that his family had actually suffered a loss. He accurately described the definition of an ambiguous loss because of the psychological absence of the individual. His understanding of the ambiguity of their loss is evident in comments like ‘the essence of who he is, is not there’ or ‘his body is there but it is really hard to see that he is still there because you don’t get anything’ and ‘you can’t see that he is there’. In Ross’s own words, it is the ‘essence of who he is’ that has gone, leaving a functioning body behind.

It was of interest to note that across these families, family members started to talk about their family member in the past tense. This is evident when Beth (F2) reminded herself a number of times during the interview not to talk about Brian ‘in the past tense’ as he is still alive. In other families, family members talked of the patient’s lost future or pointing out that ‘he was a good golfer’ (F8) and ‘he had the world at his feet’ (F5) or that the patient had ‘liked New York’ (F2) and so on. It appears that the losses these families had suffered slipped into their awareness through the use of the past tense without it ever being consciously acknowledged as loss at that time. Jones (2002) reported a similar observation in families with a mentally ill family member and suggests that this underlines the difficulties families encounter in reconciling the memory of someone, prior to mental illness, with the person today.

Accounts from some family members suggest that the ambiguity of the loss causes confusion and suffering. Julie (F3), Peter’s wife, recalled that she had accepted Peter’s loss when she was informed about the severity of his brain injury. His survival appeared to emotionally confuse her, which was evident when she said ‘but he is still alive and I feel guilty for thinking that’. Beth (F2), Brian’s wife, revealed similar emotions in saying:

‘If he’d have died last Tuesday, like – if we lived two minutes further away they wouldn’t have been able to get him round. And you’d have to deal with the fact that he’d died suddenly like that.’

These comments suggest that dealing with a sudden death is certainly traumatic and stressful but essentially part of our life experience at some point. An ambiguous loss, in contrast, leaves families suspended in time and space. There are no rituals of saying goodbye and moving on. It is expected by society and other family members that families of brain damage patients will take on caring responsibilities thus diminishing the importance of the loss suffered. Boss’s (1999) suggestion that ambiguous loss might be the most stressful of losses seems fitting. The ambiguity and uncertainty has a profound effect on family dynamics and roles. Jeff (F8) underlined this view in pointing out that his son Kieran’s brain damage ‘has changed my life. It has changed our life’. It is the extraordinary situation of losing someone and yet not losing someone, the ongoing nature of an ambiguous loss that challenged families’ ability to move on in life.

‘Mapping the future’ is a dimension of ambiguous loss, describing the impact of an ambiguous loss on families.

Mapping the future
‘Mapping the future’ is about refocusing one’s time perspective from the present to the future and thinking about ‘how to move on the map’ (Charmaz, 1991, p. 190). In families where the patient had suffered permanent brain damage, a caring scenario emerged. Future became an elusive concept. Jeff (F8) underlined this aspect of an uncertain future in saying that:

‘I’ll think forward but it’s difficult for – . There’re all the different scenarios that will come into play, but if one of us has to give up working first, it would be Fiona (wife) because I think one of us has to provide for the family - that would be a problem’.

The different scenarios mentioned here refer to contrasting degrees of recovery. These range from the patient’s full recovery to a total dependence on care, each of which requires a different response from the family. ‘Mapping the future’ therefore refers to how families refocused their time perspective from the present to the future and thinking about ‘how to move on the map’ (Charmaz, 1991, p. 190). This dimension has two further aspects: (1) the individual and (2) the family perspective.

Individual perspective
Data suggest that an emerging caring scenario had different implications for each family member. This was evident when Ross (F2), e.g. pointed out that:
'But I think that, you know, my life will just have to go back to being my life and I’ve got to move on. And I’ve got my friends and girlfriend and getting a new job, I’ve got all these sort of other things that are going to occupy my life. And I feel that you are going to have the biggest hole - (referring to Beth).'

Similarly, Jeff (F8) argued that:

'I think at the end of the day it’s easier almost it’s easier, but it is easier for myself really because I will have some sort of life no matter how Kieran (17) comes out of it. Again, Fiona for instance, might have to give up her work and look after him, which then becomes more ( ) rest on Fiona then. I can go back to my work, that’s when it starts to become harder if that’s what happens.'

In another family, Linda (F5) offers the following assessment of her future:

'But I mean as the woman in this – and a mother in this family. I have – it had occurred to me that they (Shona (20, daughter) and Andrew (husband)) could carry on with their lives but I can’t because of him (Hamish). It’s going to be me who has to give things up. And ahm it’s one of these things (quietly spoken).'

These accounts from family members of different families indicate the different impact the patient’s brain damage had on the future of individual family members’ lives. In other words, how family members could move on the map was linked to their position within the family. Although for some women the theme of becoming a carer emerged, men, children and siblings could, as Linda (F5) puts it ‘carry on with their lives’ and return to some sort of normality.

Family perspective
From a family perspective, mapping the future was linked to retaining hope for a good enough recovery, so that a total care dependency did not materialise and the family could go on living their own life but also the need to secure the family’s financial future.

In family 8, Jeff had suggested to go back to work and in probing the family’s views about his suggestion, the following emerged:

SK: ‘Were you discussing-?’

Fiona: ‘No!’

Jeff: ‘No. But at the end of the day.’

Fiona appeared to be surprised at Jeff’s comment during the interview, her reference to the difference in salaries, and the need for money to support the family suggests a pragmatic choice, aiming at securing the family’s future. The extent of changes to their individual and family lives that families had to face in an emerging caring situation was beginning to show. ‘Thinking forward’ was particularly difficult for the designated main carer.

Fiona: ‘Mhmm. It’s just coping every day instead of trying to look too far ahead.’

SK: ‘Because of the uncertainty or because you’re frightened of the future because of the uncertainty?’

Jeff: ‘Because of the uncertainty.’

Fiona: ‘Both of it.’

Accounts suggest that women found it more difficult to think forward, and their reluctance to accept the enormity of the changes which might be required to accommodate long-term caring responsibilities was apparent in interviews. It was the mother or wife ‘who has to give things up’ and Linda (F5) had already informed her swimming club, that they ‘won’t see me again because I can’t have any commitments – ever’. Similarly, while Ross (F2) pointed out that his ‘life will just have to go back to being my life and I’ve got to move on’ Beth, his mother, asked poignantly ‘future? What future?’ when they discussed the possible implications of Brian’s brain damage on their future lives. For the designated carer, ‘moving on’ involved moving towards a future of long-term caring for a brain damaged family member and makes visible the interdependence of care dependency of the patient and the impact this had on the independence of the main carer as an individual. The extent of the brain damage these patients had suffered had the potential of fundamentally changing the long-term future of their families and the individuals within their families.

The designated carers in this study were all women and with the exception of Susan (F4) approached the emerging caring scenario with reluctance. Susan, Jon’s (19) mother, took a proactive approach to the emerging caring scenario. During the interview she stated in no uncertain terms that it would be her who would look after Jon should he require long-term care. While
some family members were happy to be involved in caring tasks during the patient’s ICU stay, Susan took her involvement one step further. She argued that:

‘I had been bed bathing Jon, I’d helped them roll Jon and I was quite happy. I wanted to do that because the way I looked at it, Susanne, we had no idea what condition Jon would come through this. And I would have had to do these things for him a bit later down the line. And I just felt: ‘I’m here, I’m as well might finding out now’, you know, and getting used to it and getting over any kind of squeamishness or whatever.’

It is evident in her comment that she purposefully wanted to be involved in his care. In contrast to other potential designated carers in this study, she took the opportunity to ‘find out now’ what a caring scenario might mean for her ‘later down the line’. Across family interviews and as is evident in the family examples provided here, women were expected to, or expected themselves to, take over caring responsibilities.

**DISCUSSION**

The study used family interviews, and this article draws on voices of some families who had suffered an ambiguous loss following their family member’s TBI. Families in this study had experienced the second type of ambiguous loss, where the family member is physically present but psychologically absent. Ross’s (25, F2) description of the loss, namely that ‘the essence of who’ the person was before the TBI had gone, voices the experience of other families in this study. By substituting the word ‘essence’ with ‘soul’, understanding of the loss families had suffered is enhanced. If ‘essence’ stands for the ‘fundamental nature or inherent characteristic of a person’ and ‘soul’ is understood to be ‘the moral, emotional or intellectual nature of a person’ (Concise Oxford Dictionary, 1995), then the ambiguity, extent of the loss suffered and implications for the future of that family becomes apparent. It is the ongoing nature of the loss and the uncertainty as to what has been lost of a person’s ‘essence’ that have an impact on families and individuals within families’ futures.

The family data presented appear to support Boss’s (1999, 2006) view that the experience of ambiguous loss is particularly traumatic because of the inability to resolve the situation. It was clearly the ongoing nature of ambiguous loss that challenged these families further. Future had become an elusive concept. In contrast to death, there was no closure and no resolution. Mourning for these patients has to take place with the person physically present yet psychologically absent. In Jones’ phenomenological study, family members explained this complicated grief situation as ‘living on the edge of the world’ because it is too difficult for others to understand what is happening in families that have lost someone in such ambiguous ways (Jones, 2002, p. 51). The study families were at the beginning of this journey.

Landau and Hisset’s (2008) study demonstrates that even a mild TBI can lead to the experience of ambiguous loss. They examined the impact of a mild TBI and findings indicated that patients experienced a ‘loss of self’ which was manifested as ‘identity ambiguity’ whereas their partners or families experienced ‘boundary ambiguity’. Family members, however, ‘perceived patients’ ‘identity ambiguity’ and the subsequent changes of the patient’s essence as an ambiguous loss. Their findings indicate that ambiguous loss can have a negative impact on family relationships and can lead to the breakdown of families.

‘Mapping the future’ described the impact an ambiguous loss had on families’ futures and related to families’ need of refocusing their time perspective from the present to the future, thinking about ‘how to move on the map’ (Charmaz, 1991, p. 190). In those families where the patient was a young adult, brain damage puts the natural life cycle of launching a child into his or her own life at some point (McGoldrick and Carter, 2003) into jeopardy. In the case of family 5, Hamish (19) had already lived independently and now this step had to be reversed because of his emerging care needs. Women were the designated carers and thus made to sacrifice parts of their identity and independence for the needs of the family.

It is tempting to argue at this point that gender and power inequalities in families are responsible for this one-sided situation. It seems that the assumed ‘naturalness’ of women’s caring abilities predisposes them to take on any caring roles that emerge during a family’s life course (Bernardes, 1997). In fact, as some authors point out, the state draws on the family as the site of care as is evident in local as well as national public (health) policies (Wasoff and Dey, 2000; McKie et al., 2004). Family in this context reads ‘woman’. To see care as gendered is not a new insight (Morgan, 1996; Bernardes, 1997; Muncie and Sapsford, 1997; McKie et al., 2004). Gender, as a social structure, affects our being in public as well as private spheres of life (Morgan, 1996; Risman, 1998). In addition, power in families or marriages has been linked to money and hence inequality within families or partnerships. There is the argument that the partner with the largest
of the situation. This is what Thayer-Bacon calls ‘embeddedness’ as we are embedded in the larger social context. The feminist argument might seem persuasive but it is simply not the whole story. The intimate relationships in families, socially constructed by their embedded, embodied family members that affect each other dynamically and functionally, are the other part of the equation.

**Study limitations**

All patients in this study were male. Efforts to include families where the patient was female failed. During the time of data gathering, there were three families where the mother was the patient. In all three families the patient was either too unstable or the male partner too distressed to be approached.

It is also possible that different issues might have been raised if family members had been interviewed separately, resulting in different insights into families’ experiences with critical illness. However, it was the co-construction of the family’s experience with critical illness that was of interest in this study. In this context, it is important to acknowledge that there are some issues that are not appropriate for discussion in family interviews and therefore cannot be raised (Dale and Altschuler, 2006).

**CONCLUSION**

“If you save someone’s life, you must care for them forever – Chinese Proverb.”

Advances in medical technology have led to increased survival rates for critically ill patients. Survival has become an ICU outcome measure but survival figures do not convey the state in which a patient survives a critical illness. As is evident in this study, while patients with ICU care can survive a serious TBI, they may suffer some permanent brain damage.

Families where the patient had suffered permanent brain damage experience an ambiguous loss, a loss where the patient was physically present but psychologically absent. In this situation a caring scenario emerged which had a fundamental impact on the family’s future. The dimension of ‘mapping the future’ draws out these implications for different family members.

However, findings like these, point towards a moral dilemma. Once society decides to use ICU technology to advance survival rates from critical illness, does it then not also has the obligation to provide a framework for long-term care for those patients who survive with serve health problems or prolonged care needs?
### WHAT IS KNOWN ABOUT THE TOPIC

- Advances in medical technology have led to increased survival rates for critically ill patients, resulting in the survival of patients with serious TBI.
- The long-term impact of TBI affects the patient and the family.

### WHAT THIS PAPER ADDS

- A new insight into families' experiences of an ambiguous loss following their family members' brain injury and the impact on families' futures.
- Findings highlight the moral dilemma of the advances in ICU technology, resulting in increased survival rate of patients with brain damage, and therefore a subsequent need for long-term care for these patients and their families.

### REFERENCES


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