

The Spirituality of Recovery and the Recovery of Spirituality

Introduction

This paper arises out of primary, qualitative research data gleaned through interviews with survivors of traumatic brain injury (TBI) and with their primary caregivers. It has a deliberately bifocal perspective. First, it explores the nature of the spirituality of recovery following a brain injury. It does so from the perspective that a life-threatening event or accident will frequently cause the survivor to experience new perceptions of their own spirituality. That is to say, the ultimate questions that a survivor asks seek ultimate values. To the extent that they focus on personal significance, connecting the seen and the unseen components of their lives, and the essence of being (what it means to be fully alive), those questions may be regarded as broadly spiritual questions. They seek ultimate meaning and a sense of personal purpose for their lives. Spirituality in this loose sense may thus be defined widely to include both:

- a) a deliberate act of focused or intentional reflection upon ultimate values; and
- b) an embedded collection of ultimate values that may surface uninvited when personal loss or pain are experienced.

This paper, however, has a second area of focus. It is the recovery of spirituality. When a Christian believer suffers a catastrophic loss a frequent secondary casualty is the loss of hope. In the end, this loss may prove to be more painful to a believer than the considerable physical or emotional pain caused by the presenting catastrophe. The abrasions of a wounded spirit are deeper and more complex to heal than physical wounds. The loss of hope may cause a believer to have to redefine her/his understanding of self, God and the nature of being in the world.

Why should the loss of hope be so troubling to a believer? A biblical theological answer must recognize that the hope of the gospel is central to a biblical understanding of the Christian life. Any understanding of the gospel that omits hope is incomplete. Such a version of the gospel lacks a foundational dimension of futurity. Hope implies a future dimension because hope looks beyond the present to anticipate what is to come. Hope is a foundational biblical theme, both as a noun in the sense of “a future blessed by God”

and as a verb, in the sense of “to trust”. For the Christian believer, hope is born through faith in Christ. As the writer to the Hebrews (6:19) puts it, “We have this hope as an anchor for the soul, firm and secure.” It is a hope that goes beyond this present life to take the believer into a secure eternity: “If only for this life we have hope in Christ, we are to be pitied more than all men.” (1 Cor. 15:9)

How then does a believer recover her/his hope when a catastrophic loss has robbed her/him of hope? And what appropriate pastoral interventions might aid the recovery of hope? Those questions formed the central focus of a qualitative research project that I conducted over several months in 2000/2001. The research began after the author received a letter from a TBI survivor. With real names withheld, it says:

Dear Paul

My sister, Jane Smith, has given me your address and Email. Jane met you at an Alpha Course in London recently. I am Susan, Jane’s older sister. Four and a half years ago I was the unhappy recipient of major head injuries. I understand from Jane that you are a fellow sufferer and are keen to speak to me.

To say I would be keen to speak to a fellow sufferer is a massive understatement! I would love to talk!

Jane has told me you are writing a book for the families of head injury victims. I have often wondered why there appears to be nothing written by victims. We are on the inside looking out and no one can tell us what that is like. However, medics at all like to write books on the subject.

I have learned that my gruesome twosome of attempted murder and brain damage is a recipe for social exclusion. Sadly there are no prizes for survival. I have learned that society is more comfortable with death and disability than a middle-aged female who died at the age of forty-three and, by the grace of God, survived and walked away. Courtesy of a criminal injuries claim that has resulted in a ritual denigration of the victim, me, I have ended up feeling I am the criminal with no rights.

Survival has carried a dreadful price that is becoming almost unendurable. I knew when I emerged from a coma in hospital that I had a duty to survive. I either got a life or opened a vein. Having raised failure to a fine art form in my life I had to survive and survive alone. I am horrified that my family has had to endure my imbecilities and I feel huge guilt that I am alive. My injuries should have killed me and at best left me a dribbling cabbage in a wheelchair. Miraculously, I lived. I have been left with balance problems, no sense of taste or smell, damaged hearing and vision, a lot of aches and pains courtesy of having been thrown around

on a concrete floor and stamped on. The head injuries were sustained when my face was forced at great speed through the plate glass oven door in my kitchen. A steam iron was broken over my head. I was stabbed in the neck. I was also beaten over the head with bottles. My skull was cracked wide open and looked like an egg with the top taken off, apparently. The base of my skull was fractured, as was the top of my spine. The knife slid past my jugular and missed. My face was fractured from top to bottom. When found by the paramedics, I was clinically dead – no heart rate, no pulse but still speaking. I died several times in hospital and had several out of body experiences. I can only assume that anger of epic proportions kept me alive as I bled to death on my kitchen floor and waited in sub-zero temperatures for help. A monolithic anger I still feel against the individual who tried to kill me.

I apologize for the inevitable verbosity. Open Pandora's box and it is difficult to shut up. I very much look forward to talking to you and learning your history.

Yours sincerely,
Susan Smith

The losses that Susan sustained catapulted her into a quest for meaning and purpose, a search for hope. Her pain resonates with my own following a severe brain injury that I sustained in a car accident. Like Susan, I searched for a lost hope. Unlike Susan, I was already a Christian believer. Her pain – and my own – took me into the company of other survivors to ask what might be the best kinds of pastoral intervention to help one restore a fragile, damaged or absent hope.

General Approach to this Issue:

The goal of this study, as the title of my research indicates, is to gain an “Understanding [of] Traumatic Brain Injury and [to discuss some] Implications for Pastoral Intervention”. Our aim is to discover whether – and what kind of – pastoral interventions are possible for the survivors of a Traumatic Brain Injury and for their caregiving family members.

The project begins by establishing its focus on some important background information as the context for this current study – how it was initiated and designed. A brief discussion of some significant medical definitions introduces traumatic brain injury

as the intentional field of pastoral ministry. Brief background notes and introductory medical details are discussed to provide the context for the research and its methodology.

Significance of the Research

This project was triggered – and continues to be sparked – by personal experience. It arises from my own situation in which I awoke one day to discover myself to be a survivor of a severe Traumatic Brain Injury (TBI). Being a TBI survivor does not, *per se*, qualify one to be an expert – and on the subject of brain injury I am not an expert. Nor am I a specialist in the area of pastoral care giving to TBI survivors and their principal caregivers. Frequently, such caregivers include a spouse or another member of the family of the TBI survivor. Within my own recovery, I have found no such “pastoral expert” to exist.

However, my personal experience does qualify me in at least one area. It allows me to comment about styles of pastoral intervention – the kinds that my family and I have found to be helpful and those that we have found not to be so helpful. Some were, in fact, a positive hindrance. Such experiences have left me with a considerable amount of tacit knowledge about the kinds of care giving that might have been more appropriate. These will be compared to the experiences and insights of other TBI survivors.

Brain injury causes measurable losses and these are often part of a longer list of physical losses caused by the same trauma. My own losses, sustained through a car accident, were physical, emotional and cognitive. Beyond these medical losses, however, I experienced a loss – as a Christian believer – of my sense of a hope and a future. Although relatively short-lived, this was more devastating for me than all my other losses combined. It gave me my most intense moments of inner pain and my deepest sensation of brokenness. It gave rise to symptoms, which I can only describe as those of a ‘wounded spirit’¹. The assumption that other TBI survivors similarly lost “a hope and a future” was tested in the research and issued in some surprising results.

¹ I use this term to describe felt or expressed dis-ease of personal spirituality, a spiritual dysfunction or a sense of spiritual dislocation. Often, theological questions and a sense of spiritual pain evidence it.

A. Coding Procedures

Three hundred pages of interview transcription form a record of the discussions that took place with my eleven encoded interview subjects. They are too numerous to include as an appendix to this study. However, they are liberally quoted within this chapter in order to establish and illustrate a firm understanding of the subjects' responses, priorities and recovery issues.

For coding purposes, interviews with TBI Survivors (S) are referred to using the codes S1 through S6. Principal Caregivers (PC) are referred to as PC1 through PC5 with a suffix A or B to denote a husband (A), or a wife (B). A Family Member (FM) is referred to as FM1.

In some correspondence with victims² of TBI, I received two letters from members of the interview group. They are referred to by the addition of the suffix 'L' e.g., S1L and PC4L.

Quotations from interviews are referenced in parentheses directly following the quotation. The reference uses the subject's personal code followed by two numbers separated by a period. These last numbers refer to the page and paragraph numbers in the transcribed interviews e.g., PC1B. 15.3.

The interview group raised sixty-six distinct recovery issues. These have been grouped into six broad categories. Those categories will enable us to offer succinct comment upon them and to identify specific issues and clusters of related sub-issues within them relating to the recovery experience. The five categories are:

- 1 Losses suffered through TBI;
- 2 Emotional losses and the emotional sequelae of loss;
- 3 Cognitive losses
- 4 Family systems and TBI losses;
- 5 The spirituality of recovery.

² Throughout this study we use the word 'victim' as an inclusive term. It describes the Principal Caregiver and Family Members as well as the Survivor. Anyone whose life is impacted by a TBI is thus a 'victim'. Similarly, 'family' is used within this study in its broadest sense to denote a collection of significant others in a Survivor's life. This research group, however, happens to have a Christian and traditional family structure in each case though this was not a prerequisite for participation in this research project.

Our analysis and discussion of these categories takes account of the clusters of related recovery sub-issues within them. The research identifies a significant range of issues that is wider than the TBI experience of the present writer. Indeed, the research group lists more issues than any single interview subject alone has experienced.

The Survivor interviewees include four males aged 38, 44, 50 and 55, and two females aged 45 and 48. Principal Caregivers include parents. One parent is mother to the survivor and the other two people are a husband and wife team both of whom are the birth parents to their survivor. The remaining three Principal Caregivers are female spouses of Survivors.

B. Introduction to the Nature and Range of TBI Losses

The time-lapse from injury to interview for this research group varies from one to thirteen years. This would indicate that all of the subjects have to cope with long-term recovery issues. As one Survivor reports four and a half years after her injury,

I have been left with balance problems, no sense of smell, damaged hearing and vision, and a lot of aches and pains courtesy of having been thrown around on a concrete floor and stamped on. (S1L. 2.1e)

Long-term issues may also include learning what is required in order to adapt to long-term or permanent losses and resultant life-changes, as Survivor S3 notes, thirteen and a half years post-injury:

I'm a lot slower [as a driver] than I was before – a lot more cautious. I try to take things very careful and not go out and have another accident. (S3. 26.5)

Altered states within a Survivor's family structure and a changed position within society at large may result from his or her injuries. One Survivor reports:

I have learned that society is more comfortable with death and disability than a middle-aged female who died at the age of forty-three and, by the grace of God, survived and walked away. (S1L. 1.4b)

Family Member FM1, speaking in the context of a close, loving and committed family structure, confirms this view. She says with disarming honesty and a large degree of personal pain:

I thought, you know, she might as well be – you know – what hope is there for her? She’s this mangled person. It would have been better if she had died and it would have been easier actually. In some ways – all the things we’ve been through – it would have been much more clear-cut if she had died. It would have been nice and tidy... but this is not tidy. And I think [our other sibling] feels like that, too. Often, we both say we wish she’d died. (FM1. 10.7b)

Clearly, the impact upon this family has been both profound and unsettling. In addition to medical recovery issues, there are complex relational issues here that will not easily go away or be resolved quickly through simple formulaic answers or neat prescriptions.

FM1 also raises the issue of death, which together with suicide was a theme that was mentioned by the interview subjects nine times. S1 says when asked if she often thinks about suicide, replies:

Quite frequently – because it’s almost like it’s the back-up, like you have pills for pain, or whatever. I think it’s the – really it’s the only way out. I’d begun to see it as – the only option in terms of life is death... the only drawback is that I don’t relish the idea of waking up to another life. (S1. 17.12 & 14)

FM1 comments about her Survivor-sister:

I know she feels very suicidal... She said to me, “I realize that the only hope of escape for me was to kill myself and there is – there are other escapes.” I don’t quite know what they are but she does feel, you know, that that is slightly more hopeful than dying. I mean it is very final. – And that she’s realizing some things about herself. They are very painful things. (FM1 12.1e & g)

Such comments as these from victims serve to illustrate the degree of pain that TBI losses bring in their wake to all concerned. Survivor S3 says:

At one point I prayed and “Lord,” I said, “I will – I’ll not commit suicide. This is your handle and not mine.” And since that, since I prayed that, I’ve not had any thoughts of suicide. If God wants me to be killed He’ll do it. I’m not going to do it. And so I’ve just given my life to Him and

He's in charge, not me. So no, I haven't had that – and that's probably been six or seven years now, maybe even longer. (S3. 21.10-22.1)

The reference to God and His strengthening the resolve of S3 not to take his own life, requires that we offer some further comment about the belief systems of our research group.

C. The Faith Background of Interviewees

The values and religious faith background of this group is a significant part of this research. Faith understandings impact the responses that subjects give in their interviews.

All of our interview subjects claim to be people with a belief system rooted in the Christian faith. They do not share the same single interpretation, or a common understanding of what that means. Not all, for example, would claim to have a personal relationship with Jesus Christ as Lord and Savior.

One subject has had no church links since childhood when she grew up in a loving Christian home. She is presently looking for a faith community in which to find her spiritual home. One TBI Survivor and the Caregiver-spouse attend an Anglican Church for important family and festival occasions within the Christian year. Another survivor is disenchanted with the kinds of support she has received from her evangelical Baptist Church community and this survivor decided, shortly after being interviewed, to give up on church entirely. One couple is fully engaged in their evangelical Charismatic Church and benefit from active involvement within it. Another couple has received ongoing help from the Canadian Chinese Church in which the husband interned as a Pastor prior to his injury. Another survivor has a loose link to his own Evangelical Church but now plays a significantly less active role than he did prior to his injury.

For the reason that a brain injury is frequently a 'hidden handicap' survivors may remain unnoticed within their own church setting. Their absence from church attendance may be overlooked. Their needs may remain unseen after they make a sufficient physical recovery to enable them to resume church attendance. However, TBI Survivors

frequently remain in a long-term need of pastoral care and appropriate forms of support and pastoral intervention.

D. Recording the Relative Weight of TBI Losses

It is important accurately to hear and record the weight that a victim gives to the loss that he or she experiences. This we are careful to do within the norms of qualitative research. Clearly, there are no standardized measures to help us to do this but wherever possible we let the voices of our subjects be heard by directly quoting them in this study.

Our focus is upon the narrative accounts of Survivors and their Caregivers. This is in order to identify the range of issues of this group of victims and to hear the importance they place upon their own concerns. We recognize that the relative weight of importance that subjects attach to various issues is not constant. They are apt to change over time and even from day to day, in some cases. However, we record the relative importance that subjects attributed to their issues on the day that we interviewed them.

Subjects present their needs within their families, communities of faith and other social settings. Thus there are implications here for pastoral care. Their narrative accounts give voice to their needs more eloquently than might otherwise be possible for them to achieve in an ordinary social setting.

With this introduction to the nature and range of losses experienced by the research group, we may now examine those losses further under the six categories that emerged from the interview transcripts.

1. Losses Suffered through TBI:

1 (a) Varieties of loss:

Following a TBI, we observe that the losses sustained by this group of subjects – taken as a whole - are multiple and complex.

The losses are complex. They are physical, they are certainly psychological... and emotional... In fact, I doubt there's an area of her life that has not been touched by this. (PC1A. 1.10 & 12).

The categories of losses that were identified by the research group included self-confidence (two mentions), complex losses (eleven mentions), emotional (twenty-three mentions), cognitive (fifty mentions), physical (thirty-two mentions), long-term (three mentions), losses initially missed by doctors (one mention), and fatigue (five mentions).

The number of times a category of loss is mentioned may indicate its frequency in discussion as a loss-event for this group. However, that does not mean that a loss is less significant because it is mentioned less frequently. The *intensity* with which a loss is expressed may be the better indicator of the significance of that loss. That is to say, emotion or some other strength of expression in describing a loss and its impact may better demonstrate what it means to a particular Survivor, Caregiver or Family Member.

1 (b) Loss and its legacy of grief:

For one subject, her losses resulted from a violent personal attack, an ‘attempted murder’ (S1. 1.4). Her sister adds:

She was attacked in her home... They assaulted her in her kitchen... this man brutally attacked her – put her head through an oven door, smacked her head with a [steam] iron... did a fairly good job of pulping her head... then ran away having assaulted her... raped her. (FM1. 1.4-8)

Under these circumstances the victim and her family experienced at least two kinds of personal violation. The first personal violation relates to the actual losses sustained. The second relates to the deliberate, targeted and vicious manner in which the losses occurred. As we shall note later, this family also feels that a third violation occurred at the hands of a legal and social support system that has badly failed them. One event has thus produced multiple traumas. There is a recurring theme – one trauma, multiple losses – among our post-injury interview subjects and their families.

For Survivor S1, another profound consequential loss – and one that is perhaps easy to understand – is that “she has lost her self-confidence,” (PC1B. 1.9) because through it all “a lot of her self-confidence was destroyed” (FM1. 3.1d). However, other Survivors whose injuries were not caused through a personal attack, experienced similar

losses of self-confidence. It was certainly present in my own personal recovery narrative. This may emanate from their acute awareness of their impaired functioning, post-injury.

Caregivers and other family members, too, fully share in the sense of robbery and shock caused by sudden loss. Families are left to deal with the pragmatic, day-to-day, care-giving responsibilities in a prolonged recuperative process. Moreover, they are doing these tasks for a loved one who may have suffered personality changes and has thus become a “familiar stranger” within their family.

Caregiver PC1A reports that the TBI raises pre-existent relational difficulties that had, until the injury, remained dormant:

Old difficulties, disagreements, and things like that, which can surface as a result... It's like having a gale at sea, isn't it? I mean, the moderate wind will affect the top but when something like this happens, the turbulence goes right down to the bottom. (PC1A. 53.6)

The suddenness of the trauma produces a haunting shock that continues to resonate for a remarkably long time. More than four years post-injury, Survivor S1 reports:

...what happened to me, happened like that [snaps fingers]. Got up one morning and within an hour I'd lost everything, and I was dead. It was so fast that it sort of wiped out hope as an option. (S1. 28.2)

The finality of these losses causes survivors and their families to feel that a death has occurred. This death might be a brief clinical “death” from which the subject, as with S1, was revived and has recovered. It may also be a metaphorical death that evokes an equally intense grief-response. Survivor S3 talks in terms of the “old me who is dead” as he reflects upon the “new” person that he has become with reduced and impaired abilities:

I used to be able to do lots of things I can't do now. They hurt a lot. I'd like to be able to go back and do them. But I have to realize, that's the old [me] who's dead. The new one has to cope with what he is and where he is. And I'm trying to get away from the old things I couldn't do and I am trying just to do the things I can now and work at it. (S3. 29.2a).

Thirteen years post-injury, S3 is still working to adjust to the “new” person that he is now. His operational expectations are still geared to the old person who is now “dead” to

him. He faces an ongoing frustration of those old expectations and a difficulty in establishing new and realistic expectations of the person he is now post-injury.

2. Emotional Losses and the Emotional Sequelae of loss

We record in this section some of the emotional losses identified by the research group. We also record their accounts of recovery of emotional losses that they have experienced.

Rather than attempt to deal with the emotional sequelae of TBI losses as a unit we have noted them alongside the TBI losses (of all kinds) that created emotional challenges for this group. We refer to these emotional sequelae throughout the body of this study as we discuss the various losses that the group identified.

2 (a) Loss and Anger:

There is a frequent – and often unwelcome – task facing victims. It is getting to know this “new” person who now struggles with limitations upon her or his range of abilities. Just as death is total, so these losses feel to their victims as if a total and complete loss has occurred. ‘I’ve lost all my [law] practice and everything’ said one young lawyer, one year post-injury. (S5. 1.11b) The Caregiver of a two-year post-injury Survivor noted, “He relied on his brain and his voice and his telephone skills and all that... Something he’s lost is his ability to speak properly.” (PC2. 7.3) Typically, both the Survivor and the Caregiver continue to be in grief over these losses, as one thirteen-year post-injury Survivor reported: “I feel more grief... Just a big sadness.” (S6. 5.3&5)

Grief frequently looks like anger and frustration. Survivors may experience a new awkwardness in trying effectively to use old patterns of emotional response. Previous life skills that once were in place may now be impaired or lost altogether. As a result of his losses, as a thirteen and a half years post-injury Survivor noted:

So, skills in dealing with people and dealing with incidents, things that happen, these are all ones that take their toll on my happiness. (S3. 2.1c)

The Survivor who is self-aware must deal both with the losses of function and the emotional responses and repercussions to his or her awareness of those functional losses and impairments. Their awareness may cause them to experience intense feelings:

I suppose like anybody who's been attacked brutally and nearly died, she is depressed. She's lonely. She's suicidal. She's – you know – hopeless. I could go on... (FM1. 2.5d).

Similarly, strong feelings are repeatedly observed in the testimony of other interview subjects cited within this study.

More will be said later in a fuller consideration of anger issues. It is sufficient here simply to flag this category as being a live issue for many subjects. Emotional losses include (and may be the trigger for) some emotional instability or unpredictability, as one Survivor notes:

My emotions are usually on a very... trigger - an air trigger. They can be set off by any little simple word sometimes. And so emotions... how I handle words, talking to people – these are all problems. (S3. 2.1b)

When a victim, whether a Survivor, Caregiver or Family Member, is overloaded emotionally there are inadequate margins of emotional reserve. The overload often produces an anger-response, confusion or depression. A two-year post injury Survivor noted that his new identity creates some particular emotional challenges for him. He says, 'Emotion – [I get] easily irritated.' (S4. 9.8a). Another Survivor reports on new spiritual challenges:

I'm not sure what to do with my life and so I keep asking God, "What do you have for me?" ...I know there's more. (S3. 25.2b)

He is asking this question thirteen and a half years after his injury. This issue will not easily go away for him. His experience is not uncommon within this group of subjects. Questions about one's life-purpose and this (still) new self-identity – albeit an unwelcome, uninvited and imposed new identity – are closely related.

In the absence of answers, this group often experiences frustration and anger. They are not issues limited to the Survivor only. They also affect Caregivers and Family Members. Caregiver PC1B admits, "Yes, I'm very angry with myself sometimes."

(PC1B. 39.7) and her husband adds, “I feel angry towards some people, yes. And then I think this is wrong.” (PC1A. 39.10) He understands the tension of feeling anger, on one hand, and on the other, his consequent guilt for feeling angry. He has developed a faith-based solution for this. He says:

When we feel anger we do realize how self-damaging anger is... I mean, we tell other people, you know, anger is – does more damage to you... than it will ever do to the other person... But we do give that anger to God. We say, you know, “Lord this is how we feel... And that is very therapeutic.

Similarly, Caregiver PC3 moves her anger into prayer:

Oh, yeah. I get frustrated with [my husband]. I keep saying, “I forgive him, Lord. I forgive him, Lord. Seventy-seven times seven days.” (PC3. 17.2)

This may indicate that the normal expectations of psychologists are being fulfilled here. They are that most change in one’s experience is registered as loss, loss creates grief and grief produces anger. The more traumatic the change, the more intense one might reasonably expect the anger to be. This may indicate that pastoral care interventions should take seriously the complex anger issues that operate within the family system as a result of the trauma.

2 (b) The loss of Laughter:

The loss of laughter, feelings of celebration and fun, and the emotion of happiness proved to be a significant loss for this research group.

In addition to some volatile feelings that tip over into anger, from time to time, subjects experienced a deadening of emotional feeling. Survivor S3 reports this about his own changed emotions:

No I don’t do celebration very much. I would like to... I would like to [do fun]. I don’t do a lot of fun, no. (S3. 10.2-4)

However, this Survivor’s Caregiver-wife comments:

He’s learning to make jokes and to laugh again [after thirteen years]... That’s a new thing – and a good thing. Healing. There’s a lot of healing in laughing. (PC3. 14.9-15.2)

Caregiver PC5 reports about her two-year post-injury son's laughter, "Well, I suppose he's lost a lot of that." (PC5. 7.2) Learning how to recover "happy" as a feeling is not always an easy task, as another Caregiver-spouse notes:

Well, I guess the challenge of bringing him back to happiness... it's kind of the joyful feeling which we haven't had for a while. (PC2. 9.6)

It is important to note here that the Caregiver-spouse uses the plural "we" to tell us that the happiness of her spouse directly affects her own feelings of happiness. She, too, rides her own emotional roller coaster and whether it be in sync with his or not, her feelings cannot remain unaffected by his.

2 (c) The Emotional Impact of Losses

All losses have their emotional dimension. That is why it is necessary to refer to the issue of emotional responses as we consider each of the losses we have categorized. Losses that are sudden and severe create their own trauma-momentum.

Some of the interview group described a 'cascade effect' of losses. A devastating loss (caused here by a traumatic brain injury) puts victims in touch with other major losses in their lives. Often this produces an overwhelming grief. The sense of loss is magnified dramatically when it is viewed through the lens of previous devastating losses. The impact of the present tragedy is multiplied in its emotionally debilitating effects. The multiplication factor is the intensity of old emotional wounds from previous losses thus compounding the present loss.

Current emotional and spiritual wounds, therefore, go beyond the scope of a single trauma's ability to create them. The emotional pain extends to previously dormant losses. It reactivates the old and unresolved feelings that surround those earlier losses – in addition to the present experience of grief.

The new wounds, therefore, cause the grief and anger that are associated with past events to become active again. Those old feelings are triggered by the current experience of woundedness and they are relived concurrently with grieving over the present loss. The emotional weight of the current event is, therefore, significantly enlarged by the

additional weight of old issues. Sometimes this can be overwhelming for a victim. It may seem like a waterfall of losses is crashing over the victim's head. Deluges of emotional pain pass before the eyes of the TBI Survivor – or, indeed, the Principal Caregiver and other Family Members. Survivor S6 summed up her emotional losses in this way:

Well, emotionally, [it is] the loss of my daughter, the loss of me, the loss of my partner... I feel more grief... Just a big sadness.' (S6. 5.1).

In her accident, this Survivor's three-year old daughter died. She herself was severely disabled and her partner of fourteen years left her within a year of her injury. Her sense of grief continues to be overwhelming and her loneliness is profound more than thirteen years after the event. It is a cascade effect of losses that she continues to experience.

One Principal Caregiver (PC5. 11.3. & 15) tells a lengthy story. In it she describes in painful detail an earlier tragedy that struck another member of her family. She catalogues the emotional pain, blow by blow. She relives it as though it had happened only an hour earlier. In reality, it happened some years before. Immediately, she goes on to describe yet another traumatic incident involving her friend's son's death in a flying accident. In trying to speak about her son's injury these other emotionally painful events kept stealing her focus. Triggered by her current woundedness, earlier losses are being revisited and their pain revived. She finds it hard to stay on track.

Another Principal Caregiver comments:

Well, I think [the accident] might have been a catalyst for my emotions, you know, because I am one of those people that keeps things bottled up... You know, there's just things you remember and come back but the cascading effect that you talk about, I think misery on misery all of a sudden, like, yeah, I think this was a big catalyst that made me really miserable (*laughs*). Yeah, because my emotions, as you can probably tell, are just right on the surface – which is different for me. You know, if someone looks at me the wrong way I either get mad at them – which I wouldn't have done before – or I cry. (PC2. 20.2,8,10&12)

The overwhelming nature of such large losses, past and present, can cause emotional flooding to occur:

... Everything's just instead of being down here, it's right up here ready to come out... It specially comes out when somebody's been kind to us or helpful. In just talking to them on the phone and thanking them, I burst into tears, you know, whereas before I would have been very professional. (PC2. 21.1)

Here, there appears to be both a hyper-vigilance operating to detect perceived threats as well as an emotional rawness that produces strong responses of anger or tears or both. This is not the preferred response of this interview subject. It takes her beyond her ability to remain cool, rational and in control of her emotions. It may even cause feelings of shame or embarrassment for her.

One Survivor reports that she did not realize how much she needed to ask for help. Instead, she had tried doggedly to soldier on alone. She became aware of her striving and drivenness to retain her independence. She also realized her own ineptitude and slowness to arrive at the correct conclusion. i.e., that she really does need assistance. She reports:

That's just a resonance from the past. But, yes, I'm ashamed that it's taken me this long to realize what I've been trying to do [to recreate the old me]. Yes, it's taken me this... bloody long [four and a half years]. (S1. 22.10-12)

As things finally "become clear" to a Survivor, there is, for some, a release of joy at the clarity of new self-understandings and insights. However, there is also a sense of "what a fool I've been" and this awareness generates deep feelings of shame or regret.

2 (d) Recovering Emotional Losses:

It is important to note, however, that some emotional responses can be relearned. Subjects reported some emotional losses that are being recovered over a period of time:

Emotionally, he – it was like he was a child. He had to relearn all his emotions. The emotions in the beginning... he just sat there and he was just as happy as a lark. He didn't know anything was wrong. And then things started in and he wasn't – he was not able to recognize what this

emotion was, what he should do with it. And so, all his emotions turned to anger. Even if it was a happy noise, he didn't understand being happy. He just got angry because it was noise. (PC3. 2.16)

A survivor who is relearning old emotional skills, however, may present some emotional challenges to their caregiver:

He has a low frustration point. Sometimes it manifests itself in a temper but it's short and not very temper-like because he's always been a pretty calm guy. (PC2. 2a)

The emotions can become intensely up and down as the same spouse notes, "It's kind of really high or low." (PC2. 11.2) This altered emotional state can be a sudden and unwelcome change:

We were *really* happy before (laughs). We were ecstatic. I mean, the morning *of* we laid in bed and [our two-year old son] was sleeping in the bed across the room and waiving at us and I said (emotion in voice now) "We're so lucky," and he goes "Yeah, I know." (Deep breath) And we haven't said that (laughs and lets out air) for a while. (With emotion now) That... you know... sometimes... (Fades into a long pause with weeping). (PC2. 14.20)

Caregivers in this research group showed a remarkable tolerance and patience in dealing with their Survivors. However, the tension and tiredness of Caregivers became evident at times in their interviews:

You know the wife is kind of like... the [emotional] thermostat. If I got down he'd be even further down. You know, and if I allowed myself to lose it, it made it even worse... I just couldn't do that because it made it worse – made him worse. (PC3. 18.5c)

For this Caregiver, as for others in the group, the need to "keep going no matter what..." took precedence over her own feelings. Caregiver-stress becomes a reality that must also be managed over the long process of recovery or permanent adjustment to the new realities of life as a Survivor – and, therefore, a family – with disabilities.

3. Cognitive Losses

3 (a) Loss of Memory

The group as a whole was acutely aware of the cognitive losses that Survivors suffered and they detailed fifty references to memory loss of one kind or another. Five of

the six Survivors mentioned memory loss as being a significant loss for them. When asked if memory loss had occurred, one Survivor said, “Yes – this is short-term [memory loss].” (S1. 2.5) Her Family Member, a sister, comments:

Her short-term memory is... (pause) reasonable... I wouldn't say it's great... When she woke up from having been in a fairly long coma after being in hospital and her operations, her long-term memory was severely affected and she couldn't remember quite a lot of things. (FM1. 3.7)

Her loss remains real and apparent to others four and a half years after the injury:

She thinks she can make a cake. This is a very (laughs) odd example of a long-term – but she actually, she can't really remember how to do it... Well, my mother says to me that she'll [i.e., the Survivor will] make the cake and she does it how she thinks she should do it – so she doesn't measure anything. She just dumps everything in the bowl. And it's not great. She's actually forgotten there's a process, almost – I think – to doing things... And there are little things on her long-term memory. Some of it's fine – other bits of it are a bit bitty... On her short-term memory, I would say that there are – if something is very complicated, or it requires quite a lot of emotion, then she finds it quite difficult... Some things she manages to retain but some things she won't. (FM1. 2.5; 3.7a&b; 4.1a; 4.5.)

It is significant that this Family Member observes a link between heightened emotional stress and a corresponding greater impairment of memory function. This research finding corroborates the experience of the present writer. The difficulty that a Caregiver has in maintaining good communication over an extended period of time with the Survivor is amplified by his or her memory loss:

I am aware that sometimes you will ask her things and you know that it's about a conversation that you have had fairly recently – I mean within that day or a couple of hours ago – and she'll just look at you. And you think “Huh! You don't remember that conversation!” Or she'll repeat something when you're on the phone which is more the sort of thing I would expect from somebody my mother's age – who is seventy-five – who will repeat things. (FM1. 4.1b)

More than details, however, memory loss can rob a person of a recollection of process:

There are some things where you have to follow through instructions on things and she gets in a “tizz” and can't actually follow through some of the things. (FM1. 4.5b)

Memory loss is a common and disruptive loss after a TBI. The disruption, however, is more than a shuffled schedule of half-forgotten appointments. It may raise deeper questions of personal identity – especially when a victim can no longer remember key events in his or her own life or that of the family. One Survivor reflects upon his own memory loss:

Well, in general I've lost a lot of memory. I've lost my memory of anything that's happened since essentially 1969 forward, and I don't remember from day to day things very well. That has been getting better but it still is pretty bad. It used to be that I wouldn't remember from hour to hour what was happening. Now I seem to do that quite well. But memory is one of the big ones [i.e., losses]. (S3. 2.5c)

Memory loss interferes with harmonious communication when, for example, some agreed details and negotiated arrangements are forgotten, especially the important ones. Another Survivor reports:

I've lost a lot of memory. I know that. One of the things that I find is that I have to ask [my wife] a lot about what happened. "Who's this?" - those kinds of questions – both long-term and short-term [memory]. (S2. 1.12b)

Memory loss sometimes creates depression, frustration or anger when, for example, a Survivor realizes that an important deadline has been missed and that he or she may now be regarded by some as simply unthinking or uncaring or unreliable. One Caregiver comments about her husband:

It's hard to relearn when you don't remember what you've learnt. You end up going around the same bush many, many times. And so, that's the frustration. You know, how long is it going to take? Well, when you can't remember what you learnt the last time, everything's new. So everything's scary. (PC3. 8.1c)

Working with her husband's memory loss, this same Caregiver has developed a way of triggering memories by using key words to prompt him:

There are things he can't remember, there are things he does remember. There are also things [that] if you can give him the right key word he can find it. (PC3. 4.9)

She has even developed a helpful analogy that she and her husband have put to good use in working at developing his powers of recall:

We always talked about it [memory loss] as being that the card catalogue in the library was shuffled. The books were still in the library – but how to find them? And so, if you can get him the right word he'll remember anything. (PC3. 5.1)

Caregivers report improvements in memory and this is a hopeful indication that the initial poor memory recall is not bound, permanently, to remain so. One wife says of her husband:

Mentally, it's still improving but initially his memory was not great. But now his memory is very good. Initially, it was both [his short-term and long-term memory]. I think at about – it was at [rehab] when his short-term memory all of a sudden came back. And now, two-and-a-half years later, his long-term memory's pretty good but he doesn't remember being at the birth of our children so... sometimes I have to remind him. When I remind him he says he remembers. But he can remember his childhood and whom he has worked for over the years and most of that. And his short-term memory's, I would say, normal now. (PC2. 1.12)

Another Survivor comments upon the improvement that he has made in his powers of recall saying that whereas “in the beginning” he suffered from short term memory problems, now “it's better”. (S4. 2.12-14) His wife confirms that “in the first couple of weeks the memory [came] back.” Initially, his “short-term memory [was] bad but the long-term one he managed.” (PC4. 2.5)

One Survivor, still struggling with long-term memory loss says with longing, “I simply would like to have a memory of my – the past few years. Kind of, I don't really have a memory of it.” (S5. 8.6b) His mother confirms that his memory has improved greatly from his initial inability, two years earlier, to recall familiar faces in hospital:

He knew the family. He knew a few close friends from before but there were people who wanted to see him that he didn't recognize. Therefore at [the hospital] they drew a curtain as to visitors. (PC5. 8.6)

Another Caregiver reports a noticeable improvement in her husband's memory. She says, “It's still improving.” (PC2. 1.10b) This pattern of improvement offers a large degree of hope of some memory recovery to those who struggle with recent impairments through a TBI. Some therapists currently recommend the use of *gingko biloba* to the diet of TBI Survivors suggesting that it may fix new information in the short-term memory.

The findings of this group, as we have cited earlier, show that stress and tiredness are significant factors working to impair operational memory function.

3 (b) Multi-tasking and the Brain's Executive Functions

Another common post-injury cognitive loss is the ability to multi-task, to engage in more than one activity at a time. One Caregiver explained that his adult daughter's injury had an "effect on concentration, which leaves her very, very tired because to concentrate on more than one thing at a time is sometimes – it's too hard." (PC1A. 2.7.) When asked if his daughter was able to multi-task, this Caregiver replied emphatically, "Oh, no, not in the way she would have done before she was... injured." (PC1A. 2.9.) The Survivor herself confirms this when she says:

The minute I'll have to open a purse, pick up a bag, I've had it. I can do one thing... but the minute I start multi-tasking, physically, I'm in trouble... it's gone. (S1. 2.11)

Another Survivor with both memory loss and multi-tasking impairments reports:

Well, from what I can recall from what people told me – because I don't remember – I used to be able to do multiple things at once. A common statement that my wife makes is that I could watch television, carry on a conversation, and write lecture notes at the same time and not be interrupting any of them. Now I can't do any of that. So multi-tasking is not very good. And I don't really push it. I push trying to do one thing, finish it and then do another. And that seems to be working much better than multiple things. (S3. 8.5)

One common multi-tasking skill that is in daily use is the simple task of using the telephone. This becomes a post-injury problem to some of our interview subjects. One Survivor reports:

I don't like the telephone. It is my enemy. If I can, I would like to unplug the telephone. If the telephone bothers me or it keeps going on, I just leave. I go somewhere there is no telephone... Usually, my wife [answers the phone at home]... I will, if she's not around. I try to take a message for her because it's usually for her... Well, first [what bothers me about the telephone] is the fear of I don't know who's there and I don't know what's going on. I just don't want the phone around... It's something that interrupts me and it's an unpredictable thing because I don't know what it

is or who it is. And so it's the fear of [the] unknown coming in... So the phone is an enemy – it's not a friend. (S3. 11.11-12.1)

A Caregiver says of her husband-Survivor, "I find he's reluctant to speak on the telephone... No. He doesn't like talking on the phone." (PC2. 7.1b & 5) The telephone requires speed, comprehension and a response that survivors of brain injury commonly find to be difficult.

A telephone call usually involves a series of multi-tasking skills. It requires that someone interrupt his or her current conversation or activity in order to answer the phone. Then, one must identify the voice at the other end and engage in meaningful conversation while other interruptions may still be going on in the same room. Finally, one must remember to take a message. That usually involves finding pen and paper and writing the message while, at the same time, listening to the voice at the other end of the line. It may also require making instant decisions and giving a commitment to do something or to be somewhere at a later date. Often this proves to be too much, especially if a TBI Survivor is already tired or stressed. Survivor S1 reports:

The phone... Um... I answer the phone but all the time, if there's anything, if there's a – literally just a tissue being rustled, that's it. I can't hear a thing through the ear. It works both ways. I'll swop over – same thing. It blanks what's coming in. (S1. 10.5)

This points to another common cognitive loss. It is the ability to screen sounds so that one is able to focus on the important sounds and to distinguish them from other background sounds. When this is lost, all sound seems to demand the same urgent appeal for one's attention. It then becomes difficult or impossible to concentrate on only the important and preferred sounds. For some Survivors written messages work well as Survivor S2 reports:

I tell you, the computer for me is just a godsend – email and things like that. The Internet has been a godsend because everything is written down. I can keep a record of it and, if I need to, I can go back to it and look at it again. (S2. 2.16)

Survivor S3 contrasts written communications, such as letters, with the telephone and he observes:

Oh, I can read them – and after I’ve read the letter, I can put them away and throw them away... Usually, I put them right away – and then I read it and if it’s something interesting, I keep it; and if it’s not I put it right in the recycling bin. Yet, I still have my desk cluttered with papers that I *have* kept enough of. (S3. 12. 3 & 5)

Survivor S2 comments that the use of a written reminder has become for him an essential compensatory strategy to help him to overcome his memory impairment:

I need physical reminders like, for example, my address here. I know it’s [says his address] but there was a time when I needed that written down somewhere so I could always just check that to make sure I was right. (S2. 2.6)

Multi-tasking is a cognitive skill that falls within the general category of the brain’s executive functions. The executive functions of the brain are located in the front and temporal lobes. Executive functions include such abilities as forward planning, scheduling and organization, and keeping details together and in good order. When this neural center of the brain is injured such executive functions may be impaired. Losses of executive function also include concentration, decision-making and initiating action. Our subjects report on these kinds of losses, too. Survivor S1 says:

The worst [cognitive challenge] is concentration. Really I need to be in total isolation to concentrate properly, sort of one-to-one. But if there’s any other stuff, it’s gone. Even down to watching television – and it’s like something in Swahili. I just can’t – I know I can’t unscramble it... The messaging system is getting mixed up. My concentration for some reason just gets – it’s like that (snaps her fingers), and it’s gone and I can’t, ooh-ugh (*in disgust*). (S1. 1.10 & 11.3)

Regarding taking initiative and decision-making, Caregiver PC3 reports:

He would never initiate a conversation. If you’d say something to him he would answer you. He couldn’t make a decision. You know, I’d force him. I’d say, ‘[Name], do you want a glass of milk or a glass of water with your lunch?’ And if he couldn’t make that decision I wouldn’t give him either one because you’ve got to start with decisions somewhere simple. So I’d say, ‘You have got to decide. I’m not deciding this for you.’ So I was kind of tough. (PC3. 8.1b)

3 (c) Loss of Personal Identity

To the extent that a loss of self-understanding is a change of a perceptual focus it is a cognitive loss. The personal identity we refer to here includes two issues. The first is the self-understanding of a TBI victim and the loss of his or her previous set of self-understandings that go to make up self-identity. This self-identity includes the Survivor's physical, spiritual and emotional identity. They include those changes that the Survivor is aware of and to which he or she may react emotionally. These are issues of self-identity.

The second issue is the new identity of the Survivor in the eyes of the Caregiver and Family Members. This may go beyond the self-identity awareness of the Survivor. It may extend further than the Survivor's perception of his own self-understanding.

The emotional sequelae of TBI form a separate category for analysis purposes because the Survivor may not be self-aware regarding the post-injury emotions that he or she displays. Emotional sequelae include the emotional losses that he or she has sustained. In addition they include the altered emotional state that may now be evident to other Family Members but not to the Survivor. The altered emotional identity of the Survivor refers to the changes that are evident to him or to her.

The altered emotional state of the Survivor may place considerable stress upon the Caregiver-spouse:

I have to remind myself that I'm still healthy and happy – well, healthy, anyway. You know it's [my husband] that's suffering, but he's almost oblivious to that stuff, you know. He's, like I say, he's content to be home with us and to him, you know, he thinks that's normal – whereas to me, I don't. (PC2. 10.1d)

We note that Caregiver PC2 is careful to let inform us that “happy” does not yet apply to her own emotional condition. This statement of loss is important and significant enough for her to stress it within the interview.

Loss of one's old identity is something that is not only experienced by the Survivor but by the family as well. The loss of personal identity for the Survivor creates a loss of old corporate or collegial identities for both a married couple and the wider family, especially children or siblings of the Survivor.

Each person who is close to the Survivor experiences an ‘altered state’ of self-understanding or a displacement of position within the family. That creates changes in the interrelationships within the family structure. She or he has to negotiate a new way of being in the world and it is a forever-altered world made so by the abrupt changes that took place. They were sudden, uninvited and unforeseen.

3 (d) Other Cognitive Losses:

Interview subjects reported a variety of other additional cognitive losses. These included the following issues.

Premature aging of the TBI Survivor may become apparent to both Survivor and Caregiver. A Caregiver reports:

She has certainly slowed down as far as physical movement is concerned... I have said it on occasion – I have said it to [the Survivor] that she has prematurely aged... Every now and again [she] says something to me [that] confirms what I was thinking before about, you know, a degree of premature aging. (PC1. 2.12 & 14; 4.5)

The Survivor’s awareness of her own aging shows that she now faces issues that she might normally expect to surface later in life:

I cannot function. I need help. I cannot support myself and I’m now late forties. Ugh, it’s the lack of function. I feel I’m utterly redundant – and, yes, I am. I’m not young. I haven’t got any excuse to be alive. I’ve had – I had forty-three years before it all ended. (S1. 6.11)

Perception and recognition may become impaired, post-injury, as this Survivor describes:

Also my best trick is I can see a five-pound note as a fifty-pound note and vice-versa. I can no longer recognize... literally I can look at it and it still looks like something else. (S1. 2.11a)

Word loss or word blindness can be a persistent and troubling intermittent problem:

He sometimes loses words or sometimes can’t think of a word. And I guess sequencing of thoughts is sometimes a little muddled but he writes

beautifully and is able to organize his thoughts... He's always been a great writer and he has retained that. (PC2. 2.2b 7 4)

Reading and writing may, on the other hand, become more difficult because of cognitive losses that have occurred, as one Survivor attests:

In reading – in writing the letters – in writing the papers I find I have to slow down. It takes me more time to write [an academic] paper. (S4. 3.13)

Retaining new information, a challenge associated with short-term memory loss, becomes troublesome as Caregiver PC4 observes:

If things [are] too rushed he has a little bit of difficulty [remembering new information] (PC4. 2.7)

Academic work, reliant as it is upon the acquisition of new information, may become a particular challenge as a Survivor observes upon his return to graduate studies:

Even though I have more time [since I am no longer employed] I can only do my studies on a part-time basis. That's maybe a maximum of two to three subjects at a time. (S4. 8.2)

Fatigue is a recurring theme particularly in the early stages of recovery, though it may persist long-term:

I could fall asleep talking to someone, sometimes. I just cut out. You see I've been fighting it... because it's a sign of I'm not well – it's failure. I must fight it... I've noticed that if I just do fall asleep my head feels better... I need an awful lot of rest. (S1. 19.6,8 & 10; 21.1)

Perceptual difficulties or fatigue or a combination of both may cause post-injury confusion as one Caregiver reports, “[It] seems he had a lot of confusion.” (PC4. 2.1b)

The capacity to recover from these complex, enmeshed and devastating losses and their related consequential issues is, however, unexpectedly good for some of our subjects. One Caregiver reports:

I think that within her she has a capacity to almost re-grow and I think that a lot of this is bound up with her emotional and psychological feelings about herself. (PC1B. 2.15)

Another Caregiver, referring to initial levels of recovery, says, “His speedy recovery is beyond our expectations.” (PC4. 1.5) However, the same Caregiver is more cautious about the final level of recovery that may be possible for her husband. She says, “I know it takes a long time... and I don’t think he can one hundred percent recover.” (PC4. 5.1a)

3 (e) Recovery Issues:

A large number of other issues emerged for our research group. These include medical and neuropsychological issues, the kinds and the severity of the brain injuries that were sustained and their location within the brain.

Additional issues include the length of time that has elapsed since the injury, at time of interview; the speed of access to help upon injury, and to prompt and appropriate medical intervention; and access to appropriate rehab programs.

For some subjects the financial, stress and other pragmatic pressures upon the Survivor and his or her family were pressing issues. The research group raised these and other wider recovery issues. However, while they are important and deserve further comment they lie beyond the scope and focus of the present study.

4. Family Systems and TBI Recovery:

Significant family systems issues emerge through the impact of one person suffering a TBI. Care-giving and recovery issues therefore become complex and multi-layered. These family systems issues are important because they form the context of recovery. It is a recovery process for both the Survivor and his or her family.

Family Members – no less than the Survivor – begin their own process of massive readjustment following a TBI. Recovery may never be a return to the way life was before. Following the disorientation of the trauma a process of reorientation brings the victims of TBI to a new kind of equilibrium.

This new equilibrium may or may not be wholly satisfactory to those concerned. The areas where it remains unsatisfactory may indicate where appropriate

pastoral interventions may be helpfully offered. The issue of being of becoming “normal” was an important issue for some Survivors.

I’d assumed that I just, you know, life isn’t normal. It’s not as it was. Yes, I’d wiped out the perception that I’m normal... It’s like I’ve built up a wall around me... I don’t find other people thinking I’m abnormal and I’m amazed – but I think they are being polite. They must have noticed something. (S1. 31. 3 & 7)

“Normal” needs redefining in terms of a “new normality”, a different, post-injury way of being in the world but a way of being in which hope and a sense of a future are not impossible. When this Survivor was asked, at the end of the interview, if she had any questions that she would like to ask the interviewer, she said, “Yes, I do. Yes, certainly. Have you got to a place where you now feel normal?” The issue of being normal and the possibility for her to arrive at “normal” was important and urgent.

Survivor, S3, more than thirteen years post-injury, still thinks about what “normal” means for him now. He says,

Well, I don’t know if I will ever return to a normal pattern of work. So the delay, uh – because I probably went back to work way too soon, in a way. On the other hand, I can’t just sit and vegetate. So, the delays and problems and frustrations with that – they are there. I can’t shake them. But are they going to change and am I ever going to get normal? I don’t think I ever will. In fact I know I won’t – so why worry about it? I’m going to be who I am and I’ll have to be happy with that... Well, I look at normal as who the other [me] was, the one before the accident. He was a workaholic and he was very good. He accomplished a lot. I’m not ever going to try to do that again. I can’t do that. I’m going to try to be the best person I can and do the best job in my profession of teaching and working with people I can. (S3. 12.7; 13.1)

For Caregivers and other Family Members, too, a return to being normal can grow to be an overwhelming desire. This may be especially true in the early days of recovery. The desire to see a Survivor make as much recovery as possible may cause a resistance to accepting even the possibility that a recovery plateau, temporary or permanent, has been reached. Caregiver PC2 says of her husband,

I know what makes me happy and what brings me peace is to see him get better. And therefore I go to all of his physiotherapy appointments because when she goes, “Oh, this is getting better and that’s improved” that is what makes me feel good... And I guess I’ve found myself saying, “You’ve got to do this!” because I want my husband back. And the kids want their Dad back. “So it’s not just for you that you have to do this [physiotherapy].” (PC2. 10 1a & b)

The desire to reestablish normality is a driving force for this Caregiver that pushes her husband on in his therapies even when he himself is content to simply be who he now is. His wife needs more than his current plateau is giving to either her or to their children. Her husband’s position in the family has been radically displaced. She is not happy to settle for the plateau position that his challenges currently afford him. She will continue to work with him, energizing him beyond his own present contentment with his disabilities until he reaches a higher plateau, or level of recovery, that she feels comfortable accepting. If this ultimately proves to be impossible then there is the potential for great unhappiness, separation or an accommodation within her family to his final levels of recovery, whatever they should turn out to be.

By contrast, Survivor S4 simply accepted that “normal” describes the way he is now, post-injury. He says,

I know that people just visit me and they say that all is normal because they understand that with nerves it takes a long time for the nerves to recover – and so it is normal. (S4. 14.2)

His easy self-acceptance contrasts with the emotional struggles of the other interview subjects. It raises the question of whether he may not simply be in denial of his emotional response to major loss. It may demonstrate, however, that not all Survivors struggle with the issue of accepting their losses and the changes forced upon them. They may even find it easier than their families, friends or visitors to accept their condition.

A complex situation arises when Family Members expect the one suffering a TBI to die. FM1 expresses well her own feelings and those of another sibling upon the injury of their sister. She says,

[My sister] phoned me up and said “You have got to look at C-fax [*a television teletext news service*] on ITV for the South and find out what’s going on because

there are some things on there,” she said, “that I just do not believe. What’s – what is this?” And it didn’t seem like it was our sister... It really didn’t... And I think it felt like, um, to begin with – for both of us – that she’d died. I mean we expected her to die. All the prognoses were that she would die – and I think we were just steeling ourselves for the fact that she was going to die. And it was like – but this was not how we expected – you know how you said before, that often things are ripped – when you don’t give permission for things to happen. It felt very much like that – that suddenly buff (!) – she was out. (FM1. 9.1, 3, & 5)

Expecting a death to occur may cause one to emotionally release that person to death. It then becomes difficult to accept that the person has, after all, lived. FM1 does not admit that she released her sister to death. When asked if this were the case she replied, “No. I don’t think so.” (FM1. 10. 1). However, she goes on to express difficult feelings when she says, “And I suppose that in some ways I went through a phase where I wish she had died.” (FM1. 10 7a) This is a difficult thought for FM1 to express. It is compounded by the guilt-feelings that surround the injury of her sister and that spill over to her. She points this out saying, “[My other sister] had quite a lot of mixed feelings. We felt very guilty – apart from being displaced from our family, we both felt very guilty.” (FM1. 8.5c) When asked what is it that she feels guilty about she says,

That we actually hadn’t seen something happening and that we hadn’t actually bothered to say to [her] “What’s going on? Why didn’t you tell us?” But I suppose I felt that I’d failed her because I hadn’t bothered to ask. (FM1. 8.5c)

Later in the interview she returns to the theme of guilt. There is a large measure of it and it does not seem to have any clear definition. There is survivor-guilt mixed with the sense of “I could have done more” and a further layer of guilt for feeling that she wishes her sister had died and that she can do so little for her now. She says,

I think the only thing that I could say about my [Survivor] sister is that in reestablishing my relationship with her – and I have to work at it – I didn’t want to. – That actually I think we are at a deeper level and that the thing that I find at the moment is that I feel very helpless to help her. (FM1. 23.6a)

Survivor S1 also feels very guilty. This, in part, is due to the circumstances under which the brain injury occurred. The survivor had started working for an escort agency

in order to raise funds for a new business venture. This fact was broadcast when her attempted murder made news. There was a large measure of public shame that fell on the whole family. Survivor S1 says,

I am horrified that my family has had to endure my imbecilities and I feel huge guilt that I am alive. (S1L. 2.1c)

Guilt is a complex and multi-layered response to their circumstances for our victims. S1 feels guilt at just being alive. This is close to the guilt that other Survivors, who did not produce public shame for their families, feel about receiving a TBI.

Survivor S1 says,

Well, I feel my life has been wiped out. I don't exist anymore. And in a way, I feel somehow it was my fault because I was there (*laughs, sighs*)... I cannot see any reason to be alive. I have no function. I've completely lost any function [in life]. All I do is claim benefits, live off the state. Yes, I have no identify. (S1. 3. 1b & c)

S1 feels guilty for simply being alive in her disabled way of being following a TBI. This is a discomfort that we have noted several times.

Other Survivors have reported similar post-injury feelings as they have attempted to find their way back into a family system that they feel they have damaged or changed by virtue of their injury.

6. The Spirituality of Recovery:

A wide range of spiritual issues emerges from this group of interview subjects. They make 82 mentions of God, which we have grouped in 12 sub-categories. These include anger towards, nearness to, and new insights about God, and questions about trust, and faith. They also include God's plan, His control, His silence, His purpose and His place in this trauma, as well as personal growth in prayer, faith, hope and other questions relating to God. Raising these issues reflects a combination of factors at work for the members of our interview group. Such influences include but are not limited to the following three factors.

First, the context for their responses to their losses is connected in part to the subjects' pre-trauma understandings of God. This takes into account the nature of their

relationship to Him. Caregiver PC4 reflects a deep personal faith in God that predates the trauma. She is able to reflect theologically upon their car accident. In it both she and her husband were seriously injured yet it is she who must now care for him. She says in a letter,

Though we are physically hurt, our hearts are peaceful. We do experience that the peace that He gave us is not as the world gives (Jn 14:27). Our prayer is that Christ will be exalted in our bodies, whether by life or by death (Phil 1:20). May God's name be glorified in our lives. (PC4L. 1.4b)

A second influence is the impact of a trauma upon the victim's faith understandings, or "faith world-view". A faith world-view is an understanding of the world when it is viewed through the lens of faith. One Family Member says:

I was talking to someone the other day that isn't a Christian who is – who's interested in becoming a Christian. But she was asking me, "Why does God allow people to die and to die such painful deaths?" And I said to her,

"Well, I don't know because He hasn't been answering my questions, either." I mean, you know, "Why, why God do you allow this to happen to my sister? Is it something I did? Is it something I did that reaped this horrible, evil thing on her?" I've got lots of agenda-ey things with Him..." Why doesn't God answer our prayers?" you know, "Is it an on-going thing that we're doing wrong?" (FM1. 17.1c & d)

The third factor is a new, post-trauma understanding of who God is to TBI victims and who they understand themselves to be now in relationship to God. The same Family Member immediately goes on to say:

And I think I have – I wouldn't say I'm definite – but I think I have got to a stage where I don't actually think it's something I did. I don't understand why it happened, and I don't even know whether actually it was – whether God allowed it to happen. I don't know whether He allowed it to happen or not. But I think, for me personally, my personal relationship – as in me and God, rather than other issues and God with me in it – the thing between us is a lot more solid. I'd say my faith has grown a lot from knowing that I have, sort of – for the things I've learnt. And the things I've learnt about God, actually – that He is merciful, that He is gracious and that He doesn't leave us alone. (FM1. 17.1c & d)

Two important issues clearly stand out within her response. The first notable issue is survivor guilt. She continues to struggle with survivor guilt four and a half years post-trauma. The second notable issue is the nagging question of whether these devastating events in the life of her sister, herself and her family, are really God's punishment upon them. Are these events His retribution for some ill-defined or hidden transgression on her part? Has she brought this to pass through her own sinfulness? Such responses are not uncommon in times of personal devastation. They also have strong biblical warrant and scriptural – narrative-textual – precedent in the account of the struggles of Job.

While we continue to review and to refer to some of these new, post-trauma understandings noted by TBI victims, we offer two further comments. They are from two Survivors and are important because each is both revealing and instructive. The first is from someone who would not yet describe herself as a committed Christian in the evangelical sense of being “born again”. She says:

I fully accept that for the first time in my life that Someone up there did save my life. I actually saw in my parents' home – and I wasn't asleep – Jesus Christ stood by my bed. When it happened I thought, “Hang on a minute, Susan, [*name changed*] what are you doing? You fantasizing?” I wouldn't fantasize anyway. I was awake. I've checked, you know, that I wasn't – well, I can't tell anyone about this, obviously, because they'll think I'm completely mad. And He stood there. Real flesh and blood – not an image. Real. I didn't dare say anything. I thought, “What can I say?” And I thought, “Has He come to get me?” But I know He's not the grim reaper. But it was, uh, it still puzzles me that – of course, in line with head injuries, when you start talking about things like that, people glaze over. – “Yeah, well, this is what's happened, you know, brain's been knocked about.” But it was completely real... I do, daily, have discourse with Him. I'm powerfully aware that, yes, I've asked for help and I've got it recently, which has shattered me... Well, I think, you know we've got a world full of billions of people who need help. I mean, I'm hardly high on the priority list, am I? ...He's someone who is real. I could never ever deny the existence of God – which is a whole new experience (S1. 13.6; 17.1 & 3; 25.7)

By complete contrast, Survivor S2 seems not to have had the profound and revelatory experiences of the Survivor, above. When asked how his relationship to God

now compares to the way it was before his injury he says, “Well about the same... I don’t think it’s changed much. No, there’s been no real change or discovery.” (S2. 7.3; 11; 13)

Some subjects also experienced changed understandings of the role and the nature of the community of faith and their own place within it. After thirteen years of adjustment to significant disabilities Survivor S6 still struggles with being blind, deaf in one ear, unable to walk without the assistance of a frame, canes or other people’s support. She battles against her deep sense of loneliness. She reports:

I’ve gone through periods where I’ve had a lot of help from the people at church. But, you see, with me it’s not like a broken leg – it doesn’t get better. You have to be committed. It’s there all the time... I don’t feel included at the moment... Well, there’s two people, Barry and Jane [*names changed*] who I can phone up and, yeah, I know I am as much help to them as they are to me and that is quite good for a relationship. But there’s only three people at the church, really, I call friends. And everyone says, “Oh, Jennifer [*name changed*], nice to see you.” and all this, but it’s sort of like, on the face of it, you know? ...Yeah, it doesn’t go deep. (S6. 8.10; 12; 14; & 9.1)

It is important to note from this Survivor that she has a felt-need for reciprocity. Within supporting friendships that are effective, mutuality is both possible and desirable. The give-and-take reciprocity of mutual help and support animates and cultivates the friendship. It is as important for the disabled person to contribute to the development of the friendship as it is for her to receive help from it. She is, however, not the only victim in our research group to feel let down by the church. Another Family Member, not hers, tells a similar story.

Christians were certainly putting me off. I found I had more in common, and non-Christians were far more, um, impacted by what I said. Far more caring, far more tender, far more understanding of what was going on inside me than Christians were. And I found that scary. (FM1. 23.2)

This problem may indicate that our subjects attend dysfunctional churches. On the other hand, there may be a deeper issue to explore through further research that lies beyond the scope of the present study. That research question is how do evangelical Christians (for both of the churches they mention is an evangelical church) handle the

issue of suffering? How do they deal with the host of prickly and awkward associated issues such as anger, grief and loss? It may be that their desire to understand and explicate the faith in terms of victory in Jesus lends an unreality and even an uncaring attitude towards those in deep and long-term pain. Pain here refers to more than physical discomfort. It includes emotional and spiritual dimensions of woundedness.

There is frequently an embarrassment factor associated with suffering. Survivor S3 talks about the new person he has become and with whom he now struggles. He reports:

I'm not having a good time with that person. This person is quite forgetful. His short-term memory is bad and his temper is awful. So I'm having a lot of trouble with controlling him. (S3. 6.3)

Such embarrassment may create a need among those who suffer to apologize for the inconvenience they feel that they are causing to others. It causes some people, who look in on those who suffer, to feel impatient at the length of time that recovery seems to be taking. They fear that the current plateau of improvement in the injured person may really be a statement of her or his laziness or a form of attention-seeking behavior.

The person in pain is often hypersensitive to such implied criticism. A Survivor frequently tries to over-compensate for his or her losses. To receive such criticism drives the embarrassment of suffering and pain even deeper.

Being embarrassed with chronic, long-term suffering may even create a perception that the injured person is deliberately insulting or is radically questioning the folk theology operational within such churches. Such a theology focuses upon triumph over all adversity. Deep suffering has frustrated the desired happy-in-Jesus conclusion and the person who suffers may not yet be in a place to give a testimony of "victory through Christ". Indeed, their faith may seem faltering and weak in the public view, to those around them within the church.

By sharp contrast, two Survivors, record that they came to personal faith in Christ as a result of their experience of brain injury and their journey of recovery. One Survivor says of that experience,

[God's] been right there in front. Now, He wasn't all the time. But since I found Him – that's what's the most important thing. He is everything, right now. God – or else Jesus Christ – He's right there. That's all I can depend on – I can't depend on people. Uh, my wife I can normally depend on – but He's much better. (S3. 14.3)

Many interviewees found it difficult or impossible to distinguish between the health of their faith and the emotional barometer-reading of their feelings. It was a challenge for them to verbalize the difference between their emotional and their spiritual responses to personal suffering. When their feelings were positive so was their faith and vice versa.

Some subjects found God to be silent to them at times. One Survivor says that God is “Sometimes more active; sometimes silent.” (S2. 15.4), and another says, “I've experienced the silence.” (S3. 27.6) For others He was very present to them. When asked where God is for her, one Caregiver says, “Right here in the middle of it... I'm close to God.” (PC3. 15.6-8) One Survivor, admits that she hears God's silence. She goes on to interpret it and flatly says, “He's got nothing to say.” (S6. 11.4) However, when asked if that makes her feel that He has abandoned her she replies, “No. And even now [thirteen years post-trauma] I still know He loves me but I just don't feel I can talk to Him.” (S6. 11.6)

Her response raises the question of whether God's silence towards her is not simply a reflection of the depth of her current silence towards Him. Her spiritual loneliness may be linked to her clinical depression and its accompanying feelings of isolation. This suggests that further exploration with our subject may be helpful to gain her further clarification on this point.

Each of our subjects drew a measure of comfort, however, from their belief that God is personally interested in them. Some, going a little further, say that He cares for them and that He can make real and measurable differences in their lives. On the other hand, some feel that prayer does *not* bring measurable changes. Instead, they feel that prayer is only designed to help the one who prays to feel a measure of peace. However, knowing that other people are praying or have prayed for them and for their families was

a great comfort to all of our subjects. Caregiver PC4 asks people to continue to pray for her family. She says:

You prayers, words of comfort and encouragement and visitation are great supports to us... Please keep on praying for us, especially that we can have a strong faith in Him. (PC4L. 1.6 & 7)

PC2 also speaks affirmatively about the role of others praying for her family situation.

She says:

[At church] there is always a dear old soul, "Shall we take him off the prayer list?" - "No, not yet." (*laughs*) "Keep him on - we're not finished yet... Yeah [the prayer chain] was encouraging. It felt productive and, well, I think it worked in many ways, you know. (PC2. 19.11)

A striking tendency emerged within our interview group. It is to view their experience of suffering from within a distinctively spiritual dimension. That is to say, while there are many perspectives on their trauma, each is able to speak of the spiritual dimension as one that they have already reflected upon deeply. This appears to be true regardless of their strength of faith (or lack of it) prior to their trauma. Indeed, two Survivors claim to have had no Christian faith prior to their injury.

Somehow, their experience of suffering has pushed these TBI victims towards considering and asking some ultimate questions. These are questions about life and death and about the meaning, purpose and direction of their lives. This seems to be as true for Caregivers as it is for Survivors.

There was a general consistency for this group in their basic attitude of non-anger towards God, with just a few exceptions. One Caregiver says about his daughter's injury, "I certainly wasn't raging against God at that time. There was no feeling of that..." (PC1A. 17.15) In contrast to anger against God, his wife confirms his position. She says, "We felt He had the matter in hand... He taught us to trust Him." (PC1B. 18.1) When asked if she ever got angry with God she replied, "I can't say I ever got angry. I have been disappointed. I've felt a bit let down sometimes, but not angry." (PC1B. 38.15) The Survivor's sister says, "I found God very near and well, the word that comes to mind is an ever-present feeling." (FM1. 16.4) Later, however, during the four years and more

since her sister's injury, she has begun to feel some anger towards God at times. She says,

My feelings overtook me and I did begin to think, "Where is this God?" I was very aware that when my son was born I felt very frightened and very alone. I felt that everything had deserted me, even God... Whether I feel like God is there or not is a complete irrelevance... because I know that He's there – because otherwise I wouldn't have got through it. But it's hard, and I do feel angry towards God. (FM1. 16.6 –17.1)

While not angry with God, her Survivor-sister nonetheless places the center of her emotional pain within her wounded spirit. She says,

I suppose I've never thought the injury was wholly there [*points to her head*]. It's in here [*points to her heart*]. I've tried very hard to turn it into a simply neck up [injury] but no... Well, it's injured me, the person, not just the equipment that runs it. (S1.37. 5-9)

Her parents continue to draw some considerable comfort for themselves from the way that they saw evidence of God's presence during their daughter's first admission to hospital. They say,

We had seen God's healing hand in "Accident & Emergency"... on that first night... when we were called to the hospital, because we prayed over [her] prostrate body. And we saw almost a ripple of light go through her body. (PC1A. 17.15-19; 18.4-8)

Their daughter is quite adamant when asked if she ever gets angry with God. She says, "No. No, I never do." (S1. 29.2-4) However, she is equally firm when asked if she gets angry with herself. "Oh, yes. Yeah." (S1. 29.2-4) Her mother comments,

I remember praying for her. We put a hand on each shoulder and it was very strange, because all the medical team – I suddenly realized they had formed a half-circle behind her... to give us space... and we just prayed. It was a very simple prayer. I thought, "What on earth am I going to say?" I thought, "I've never done this in public, Lord. What am I going to do?" And all I asked for was that God would send his healing Spirit through [her] and I thanked Him, and that she would live and recover. And we saw a sort of ripple go right through – from the top of her right through to her feet. It was quite extraordinary. (PC1B. 18.9,11 &13)

These parents gain a deep hope from their faith in God's personal concern for their daughter and for their ongoing post-trauma situation. The Survivor's mother puts it this way,

I am reminded of that one line from a hymn and all I can say is "All my hope in God is founded." God is hope, and I know why you would call that a "journey of hope," because it's our main focus. We don't know what's over the next hill. We think we plan our lives – we do everything. But God is in charge and He doesn't do anything unless He knows what's going to happen. And it's that acceptance and knowing that we're safe in His hand. He is our hope. (PC1B. 36.8)

This affirmation of hope through faith in God contrasts sharply with the response of one Survivor who (thirteen years post-injury) is weakening in her faith in God. She says,

I'm a long way from God at the moment... I didn't think of God being in it at the beginning, but He came into it about ten years ago [*when I made my commitment to Christ*]. But I think now I've walked away. (S6. 5.9 & 17)

Significantly, when asked if she gets angry with God, she says. "No, because I think 'Why get angry with God?' " (S6. 6.3) She does admit, however that she gets angry with herself and concedes, "I just get annoyed with myself... but now there's not a lot that I can do." (S6. 6.7-9) By contrast, Caregiver PC1B says, "I trusted Him to save [her]." (PC1B. 23.6) Her trust, in her case, was not in vain. The real arena where trust continues to demand from her a consistency of faith, is the extended the recovery process. Her husband reports,

Well I think God has taught us to trust Him and that He answers prayer and that we are able to trust Him. We have to hang on, I mean, sometimes we hang on by our fingernails, our eyebrows. (PCB. 33.4)

Such an exercise of trust, of forced reliance upon God *in extremis*, brings for many of our subjects the discovery that He can, after all, be trusted. Such trauma may produce positive spiritual growth. It may not be the only – or the preferred – route to spiritual growth. It does, however, cause many in this research group to move forward in their faith and to test God's care for them and prove His reliability in their lives. One

Caregiver says, “Yes. I mean, I feel I have grown, by God’s grace.” (PC1B. 34.5) Both wife and husband report that they have grown in their relationship with God since their daughter’s injury.

When monitoring physical pain in hospital, patients are regularly asked to give their pain level a score out of ten where ten is the maximum pain possible. We have adopted this methodology in relation to emotional pain and spiritual pain. In each interview we asked our subjects to score their pain. Scores were given for physical, emotional and spiritual pain. It is important to note that their scores are purely subjective. However, the victim remains the “expert” on his or her own pain.

The question then arises, when is some kind of pastoral intervention indicated in order to relieve pain? For medical practitioners in palliative care, the answer is that intervention is indicated when there is a sudden upward movement in the level of self-scored pain.

In pastoral ministry, following this kind of protocol might help us. We could take a similar approach as a working model for pastoral intervention. When a victim’s emotional or spiritual pain rises significantly that upward change in pain level might be taken as the indicator that it is time to offer pastoral interventions of one kind or another.

Using a subjective ten-point scale, we asked victims to measure their closeness to God. A Survivor’s mother, PC1A, moved from 4 (pre-injury) to 9 (post-injury) on a ten-point scale where 10 is the closest to God. She says, “I’m more sure of God. My foundation is deeper. It’s stronger. I know that my Redeemer lives.” (PC1B. 34.7 & 9) Her husband moved to an 8.5 though at times of stress he feels his closeness to God goes back down to 5. He says,

I mean there are times when I, when I do doubt. I think, “Is this all pie in the sky?” And that it can [be] and then the answer comes back, “Of course not, you know – it cannot be.” And there’s so much, which we don’t understand, and we just have to stay with it... And the will to stay with it is there. (PC1A. 352 & 4)

He offers this summary-statement,

I think it has made me grow in my faith and it certainly hasn’t diminished my perception of the spiritual element. I think I have come to understand

more and to feel God's presence more... It's almost like the comparison between bone and muscle. If you use your muscles, if you are challenged, and this is what we are talking about here – our faith was challenged – the core, the bone, actually gets stronger. And it has (PC1A. 33.7; 35.11)

New understandings about God extend to the Survivor who, in this case, arrived at her injury without a prior faith in God. She says,

These sorts of God incidences are really remarkable... He's someone who's real... I've learned that whatever you've done, whatever you perceive yourself as that doesn't matter as far as God is concerned. (S1 24.2; 25 7)

Her new spiritual insights are also noticed and confirmed by her sister who reports,

And she sees God in her [situation]. She says, "You know, I do pray to God and I have seen Him helping me." And recently she's seen a lot. She says, "I *really* have seen God helping me." (S1. 13.1b)

Caregiver PC4 comments, "God comforts and encourages us in time of difficulty." (PC4L. 1.4) Comfort and spiritual encouragement came for some of our subjects through prayer and Bible reading – either reading it themselves or having it read to them. Regarding prayer, Survivor S3 says,

I'm not having a good time with that person [the new one that I have become]. This person is quite forgetful. His short-term memory is bad and his temper is awful. So I'm having a lot of trouble with controlling him. What I've found is that I can't control him and so I give it to God and he can do it. And so, my relationship is not with that person anymore – it's with God. And so I just go to Him every time I have a problem. Now, my biggest problem is I don't remember to go to Him sometimes – I just blow up. And so I've just got to keep in my mind always – whenever I'm having trouble with this person, "God you take care of it. You're in charge." And if I do that and I go right to Him, it's solved. (S3.6.3a-b)

At other times, however, the same Survivor says that in prayer he hears God's silence and that he feels there are no results. He says, "Sometimes I'll feel there's nothing happening." (S3. 28.1a) His wife, however, remains very positive after thirteen years of care-giving. She says,

Who is God for Me? Well, an ever-present help in time of trouble. He's right there and just full of love all the way through it because He has a

plan to – to perfect us through trials. And I've learnt to count it all joy...
The battles begin when you get into the Promised Land. You know, in the
desert there are not a lot of battles. It's when you get in to the Promised
Land that the battles begin. So, we're in the end and the battles come.
(PC3. 16. 5 & 7)

What is very apparent in many of the comments that we cite here, is the evident
and deep level of pain experienced by all who are closely involved in the recovery of a
TBI Survivor. It is this pain that indicates a wounded spirit and that the victim could
benefit measurably from appropriate pastoral interventions.

The question then becomes, what are the appropriate kinds of pastoral
intervention that Chaplains, Pastors of Hospital Visitors might offer to Survivors,
Caregivers and Family Members? Our answers to this question form the content of
another research paper in which we seek to bring some conclusions based upon these
research findings. In it, our focus is to offer some recommendations for appropriate
pastoral interventions and some specific suggestions for further research.

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