Suffering over Time

Patient Journeys following an Adverse Event (AE) in Victorian Public Hospitals, Pathways Undertaken, and Perceived Outcomes.

Submitted in total fulfilment of the requirements for the degree of Doctor of Philosophy

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January 2017

Printed on archival quality paper
Acknowledgements

Professor Lynn Gillam and Dr Therese Riley have been unstinting in their support over my protracted PhD journey. I offer heartfelt thanks to both for their faith in me, and in my research.

My research would not have been possible without the co-operation of the Victorian Managed Insurance Authority (VMIA), through the auspices of their officer Dr Jack Bergman, and the Office of the Health Services Commissioner in Victoria (HSC), former Commissioner Ms Beth Wilson and senior officer Ms Lynn Griffen. My Hospital based research was made possible with the collaboration of Dr Michael Buist and Research Nurse Maryanne Sparrow.

I thank friends who have walked with me on the PhD journey, Debra Knight and Margaret Norman in particular, for their fortitude, sound advice and kindness.

Finally, I want to acknowledge the 33 people, my participants, who trusted me as a researcher with the stories of their AE experiences in the hope that my research findings would contribute to a better understanding of patient needs following an AE.

Dedication

To my parents, John (deceased), and Helen Raselli.
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Abstract

An adverse event (AE) is an injury suffered by patients during hospital stay that is unrelated to their underlying, hospital admitting condition. The incidence of, and statistics about AEs, have been documented in previous studies. An AE is a patient experience that has been typically medically defined, managed, reported on and defended by medical practitioners. An AE experience from a patient perspective, considered over time, has not been previously researched, and documented.

My study involves 33 public hospital participants who suffered AEs and took different pathways to address their concerns. In a 2 stage interview process over 3.5 years, I examined the pathways taken, the reasons why they were chosen, and the perceived outcomes.

I found that the ontological assault and existential pain caused by a medical mishap or medical error was felt by participants as a betrayal of trust on the part of a particular doctor, and/ or the hospital system. Acknowledgement by the doctor of the patient as a person who had suffered an AE is the key to personal recovery, in the absence of which participants remain angry, with a desire for moral accountability, the moral element of which is not found in the complaint or legal system pathways often taken in frustration and at personal cost, broadly defined. “Healing” after an AE requires acknowledgement of error by the doctor and personal engagement with the patient at the time. This is not simply a formal apology protocol process. It requires an opportunity for patients to hear from the doctor and to reconcile their expectations of the doctor patient relationship with the reality of medical error and mishaps: forgiveness takes place in a relational context. Formal complaints and legal action taken by patients reflect a breakdown of an assumed doctor/patient relationship.

My research findings will inform and be of benefit to medical practitioners and medical indemnity insurers, and in so doing improve the experience of patients who suffer an AE during hospital stay. Patients who have suffered an AE can be forgiving, provided they are given the opportunity by doctors to do so.
Chapter 1:

Introduction and Overview

Patients admitted to a public hospital have expectations of good treatment and care. When things go wrong, expectations are confounded. Adverse events (AEs) happen within a social setting of rules, regulations, protocols, trust and expectations, which may not always be in alignment, and can end in conflict as between hospitals, doctors and patients respectively. They are all in the mix together.

My research began when I was paged as a Pastoral Care worker at a major public hospital to counsel and comfort a couple whose expectations of the birth of their first child had been dashed by an emergency caesarean section during which procedure the mother nearly died as a result of a medical error.

I sat with the couple and witnessed 2 interactions with medical staff. The first was with the Medical Registrar who exuded confidence that all things were now well, mother and baby safe, with a reassuring pat on the arm. There was anger and resentment in the room after he left. Then there was a knock on the door, and the anaesthetist entered. She stood at the foot of the bed, looked and sounded sad that the procedure had not gone well; indeed, as the patient had heard “I think I am losing her”. The anaesthetist explained her own circumstances on that Monday morning, being paged for an emergency as she was driving to work, her “head” as she put it, still in the weekend. The mood in the room changed from one of repressed anger to a quiet mulling over of events.

My observation of this interaction between a patient, her family and two doctors who took different approaches to the patient following an AE was the genesis of my research interest, and provided the foundation stone for my thesis.

Subsequently, and after resigning from my position, (a decision unrelated to my study), I contacted a number of agencies in order to test whether there was interest
in investigating AEs, the incidence and causes thereof in a Hospital setting. I did so against a background of data that had emerged about AEs, media interest in high profile litigation against doctors and payouts from medical indemnity. The Institute of Forensic Medicine was willing to assist me with my research because of its role in the investigation of AEs leading to death. Tertiary hospitals did not want to engage because of a fear that openly discussing a medical error would expose them to potential litigation.

My next step was to contact the Victorian Managed Insurance Authority (VMIA), being the public hospital insurer in Victoria. It was clear that a hospital based study of AEs was not going to be possible without VMIA backing. I made contact with senior officer Dr Jack Bergman, who in turn introduced me to Dr Michael Buist, a senior clinician at a major public hospital. We all shared an interest in the findings of the Veteran’s Affairs Hospital in Lexington Virginia, United States where a disclosure of medical error and an upfront offer of compensation had been reported as assuaging patient anger and reducing incidents of litigation. My formal research began as a study of adverse events, funded in a modest way by VMIA, in terms of a salary contribution towards a research nurse monitoring AEs at the hospital site. Importantly, VMIA indemnified the hospital site against any legal/patient claims that arose following an OD process. It was only with that assurance that the Hospital Research Ethics Committee approved a limited study that was a precursor to OD studies in Australia.

The definition of an AE for the purposes of the study was set by VMIA being an unplanned operation, unplanned intensive care unit (ICU) admission, and an unexpected extended length of hospital stay or an unexpected readmission to hospital. These were the signposts used in the retrospective, and hospital record based, seminal studies, to identify the incidence of AE’s in hospitals in the United States and Australia: the Harvard Medical Practice Study (HMPS) (Brennan, T.A, Leape, L.L , Laird, N.M, Hebert, L, Localio, A.R, Lawthers, A.G, Newhouse, J.P, Weiler, P.C, and Hiatt, H.H ) in 1991 and the Quality in Australian Health Care Study (QAHCSC) ((Wilson, R M, Runciman, WB, Gibberd, RW, Harrison, BT, Newby, L, and Hamilton, JDI) in 1994. The definition of an AE in the literature was medically defined at the outset, and actual incidents identified through patient records by Registered Nurses (RNs). The key difference between the previous
studies and that conducted under the auspices of the Hospital was that the Hospital trial was current, rather than a retrospective paper based review of medical records. My first interviews with Hospital participants were conducted in the Hospital and in the second round, with continuing participants, in their homes.

The term AE “adverse event” is, I contend, a euphemistic one. An”AE” is a way of describing a medical error which causes the least offence to doctors. The term “AE” diverts attention away from doctors, and generalizes the patient experience, as a risk associated with being in hospital and having a procedure undertaken. The use of language such as “medical error” as distinct from AE would likely have been strongly resisted by the medical profession and hospital indemnity insurers at the time of the OD trial in Australia, particularly in view of the statistics that had emerged from the studies referred to above. The Lexington Study (Kraman, SS and Hamm, G, 1991) offered an “open disclosure “of medical error, as a pre-emptive strategy, that worked for a particular group of patients, being returned U.S military veterans, which appeared to reduce the risk of litigation, and cost payouts to the Veterans Hospital Administration system. The Lexington study of an “open disclosure” of medical error and an upfront offer of monetary compensation provided the template for an open disclosure trial in Australia, that was adopted, but without the automatic financial compensation aspect.

I use the terms AE and medical error interchangeably in my thesis because I have focussed exclusively on the doctor and patient relationship following a surgical error. In my use of these terms, AE and medical error, they refer to the same phenomenon. My research and findings do not include “adverse events “caused to patients by other health care professionals who may have been involved in participants’ care, or slips, falls or drug maladministration during hospital stay, and indeed I am not aware of any of these taking place, concerning my participants.

My initial research question was whether an OD of an AE to the patient would assist the patient’s recovery and deter potential legal action, following the Lexington example, which was subsequently trialled and adopted in Australia. I extended my research inquiry in order to encompass two groups of former public
hospital patients who had experienced an AE and taken action, by way of formal complaint or legal action. These participants introduced a time element to my research because they were 2 to 9 years distant from their AE but wanted to talk about their experience. My research evolved into a qualitative study of the impact of an AE suffered over time, using semi-structured interviews with participants at two time points. The first interview round was conducted in 2003 and the second round, with continuing participants, took place in 2006. I draw attention to the time frame because whilst not initially planned on my part, the time interval provided an important research finding.

The extended passage of time between my first and second round interviews was due to personal circumstances beyond my control and explained to continuing participants in the second round interview. The originally contemplated 6 month interlude between interviews extended to several years. The time interval proved to be a benefit as it allowed participants a period to reflect on their AE, particularly the Hospital group, but all participants brought something new to the second interview. They were living with the consequences of their AE. Participants had reflected upon the initial assumptions and expectations they had about the medical profession and the hospital as a safe institution. The fact that participants were willing to talk to me, years after our first interview, and even more years after they experienced an AE, speaks of a depth of feeling and pain associated with the AE, which hadn’t gone away. Participants remained hopeful that research such as mine would make things better for future patients.

The formal research question addressed in this thesis is: “How do patients experience and understand an AE in the long term?”

The specific objectives are to:

1. Explore the effect it had on their lives;

2. Explore the meaning that they ascribe to it;

3. Investigate the actions taken (or not taken) and the reasons why pathways were chosen;
4. Explore the factors and or interventions that may assist in meeting patient needs following an AE.

My overall aim is to identify ways to improve the experience of patients who suffer an AE during hospital stay, both in the short and long term. This is important research because individuals enter hospital with an expectation of good care and recovery from the admitting complaint or illness. However, AEs happen not infrequently, research reporting a 3-18% rate of occurrence associated with hospital admission (HMPS 1994 and the QAHCS 1999 referred to previously). Even at the lower end of the AE scale, using the VMIA definition which allowed the study to proceed, patients felt harmed by the medical treatment received during their hospital stay. Information and statistics has been forthcoming about AEs since the 1990’s yet the problem remains. Baines (2013, p.290) reported an increase in AEs in the Netherlands, particularly associated with surgery.

There have been many studies about AEs typically focussed on statistics, causes, prevention and OD protocols, practice and implementation (Idaema, 2008 and 2011). There are very few studies about patients’ perspective of AEs. Mazor (2013) reports a patient study of apology and disclosure for cancer patients, but this imposed a framework of pre-set categories derived from standard OD principles, rather than allowing open patient voice. The patient experience of illness, on the other hand, has been well reported: Frank (1995, 1998, 2000); Kleinman (1988); Cassell (1978, 1991), Garro (1992). My research will find out more about the patient experience following an AE, the impact on participants’ lives, and how it shapes their decision making or world view going forward. I am particularly interested in the pathways undertaken by participants following an AE, the reasons why they were chosen, and the perceived outcomes.

The passage of time is a critical aspect of my study, from the time of the AE, to my second interview with continuing Hospital participants. It is also critical for an analysis of the two other participant groups, HSC and VMIA, providing time and reflection for them following actions taken and outcomes perceived. The overall time span of the study started at 48 hours after an AE and extends through a 2-interview timeframe over 3.5 years. The AE journey for some
participants began 4 to 8 years before our first interview.

A documented history of the patient experience and perspective following an AE, over time, has not been previously undertaken.

In the following section, I provide a brief overview of my thesis.

**Overview**

In this thesis, I will argue that participants experienced an AE as an ontological assault that caused existential as well as physical pain. A patient’s world view is turned upside down by an AE. It challenges assumptions about care and trust in doctors and hospitals. It was felt by participants as a betrayal of trust on the part of a particular doctor, and/ or the hospital system.

Acknowledgement by the doctor of the patient as a person who had suffered an AE is the key to personal recovery, in the absence of which participants remain angry, with a desire for moral accountability, the moral element of which is not found in the complaint or legal system pathways often taken in frustration and at personal cost, both emotionally and financially by participants. I argue that “healing” after an AE requires acknowledgement of error by the doctor and personal engagement with the patient at the time. This is not simply a formal apology protocol process. It requires an opportunity for patients to hear from the doctor and to reconcile their expectations of the doctor patient relationship with the reality of medical error and mishaps: forgiveness takes place in a relational context.

**Chapter 2: Adverse events: A Background**

In Chapter 2, I document by way of background the empirical research work that gave rise to the identification of an AE as an epidemic in health care costs and patient safety statistics in the United States, and Australia so much so that the respective Governments took notice and acted in ways to reduce costs. Whilst
patient safety and associated statistics were headline issues, the underlying concern was one of cost to the public health system, hospitals, and medical practitioners through increased medical indemnity premiums. An “open disclosure” protocol of medical error to patients was identified as a potential financial and reputation solution: a means to an end.

**Chapter 3: Hospitals and Doctors: Adverse events as a medico-legal construct**

In Chapter 3, I consider an AE as a medico legal construct within the context of the Western medical model. The public hospital was, and is, a public institution with a social history and an associated set of expectations. It provided the platform upon which medical practitioners laid claim to professional status originally, and it continues to be the sentinel training ground for junior doctors in the 21st century. The culture of medicine is linked to the training, experiential learning, and pioneering doctoring undertaken within a teaching hospital environment. Hospitals and doctors have historically been twinned and remain so, though the balance of power in the relationship has shifted over time. The Hospital is where the accountability of doctors has been called into question in the 21st century, requiring new styles of doctoring, in an age of an economically driven hospital management model. AEs are suffered by patients, but reputational damage occurs to the clinician and the hospital institution when it occurs on their watch. This may inform and influence responses to an AE.

**Chapter 4: A Theory of Patiendhood**

In this Chapter, I introduce the theoretical framework of my thesis which revolves around patiendhood. I discuss the theory under four headings, being the social role of patiendhood, the patient experience of illness as a loss of ontological security and trust, the different perspectives of illness as a patient’s lived experience and a doctor’s perception of a disease, and finally the need patients feel to make meaning out of their experience. The way in which patients are positioned and framed within the existing literature is one subject of this Chapter and discussed within my theoretical framework. I begin with the old and new models of patient hood, reflecting a transition from the traditional, passive sick
role in relation to the treating doctor, to a position of purported patient empowerment whereby there is an expectation of patient engagement in medical treatment options and some personal responsibility for health outcomes. This is literature looking from the outside in, on being a patient. The inside story of patienthood is told by the patients themselves. Patient narratives, typically, have been written from the perspective of patients suffering from a chronic illness and by doctors who find themselves in a role reversal as a patient with an illness.

Whilst my thesis is not a narrative analysis, per se, patient stories and perspectives are front and central in my work, as is the element of time: time for reflection about the impact of illness, and in this case an AE, on one’s life. The human spirit in adversity is a common theme.

Chapter 5: Methodology

Having set the scene in the first 4 chapters, I turn to the methodology for my study in Chapter 5. I undertook a qualitative study, informed by a number of academic disciplines. In this chapter, I document the underpinning ontological and epistemological assumptions of my research based in the interpretive tradition of social research. I outline my research plan and my recruitment process of 3 groups of patients, 33 in total, who took different pathways to resolve their AEs. I undertook a 2-stage interview process over a period of 3.5 years. I subjected my data to qualitative analysis, using techniques of thematic analysis. I then represented the key themes in the form of a simple diagram, and mapped participants against each point of the diagramme. This mapping is supported in the abstraction of the 4 key themes into a model that explicates the dynamic relationship between the themes.

Chapter 6: The AE Patient Journey

In this Chapter, I begin the presentation of my findings and analysis by introducing the AE experience from a patient perspective as a chronological and staged journey. I use first person quotes extensively and deliberately to give patients a voice, and in order to understand the feelings, repercussions and actions taken following an AE. I group the reflections under a range of thematic
headings that illustrate the breadth and depth of an AE impact, which has a ripple effect on the lives of patients, touching many aspects of life, usually involving family and friends. I draw on the work of Parsons in order to highlight a passive patient role and the “asymmetrical relationship” between patients and doctors (Parsons, T., 1951, p.33). In this Chapter, I also refer to the work of Arthur Frank concerning the personal, patient experience of illness.

Chapter 7: Participant Reflections on their AE Experience

In this Chapter, participants reflected on the losses associated with their AE. In the first instance, there was a loss of trust in doctors and the health care system that had let them down, or failed to meet expectations. The sense of disappointment and frustration continued for participants who lodged a complaint or took legal action because the “process” did not deliver what they wanted and expected, which was an engagement with their doctor. The “process” constituted a second AE for some participants, who had to defend themselves and the legitimacy of their complaint. The work of Giddens A, (1995) informs this Chapter in terms of the ontological insecurity that participants experienced following an AE. I also draw on the work of Vincent, who described what motivates patients to take legal action (Vincent, C., 1994). These themes are inter-linked.

Chapter 8: The 4A’s and a 4A Model, Pathways to Anger or Resolution

This Chapter explores the 4 recurrent themes that emerged from my thematic analysis. These themes were acknowledgement, accountability, apology and a default position of anger. I note the linkages of these themes with literature examined in Chapter 4. I call these the “4As”. In diagrammatic representations, I demonstrate the dynamic interrelationships between the 4As. Acknowledgement of error is the key to a satisfactory outcome for patients following an AE, and that requires a direct engagement and open exchange between the patient/former patient and the doctor concerned.

A formulaic apology may be given, according to OD protocols, yet the patient
remains angry because the doctor concerned either does not deliver it personally, or if he/she does, the language used may be constrained so as not to admit fault (fault in a legal sense because of medico-legal constraints and maybe fault in a personal sense).

A patient, through a formal complaint process or a successful legal action resulting in a compensation payment, may achieve technical accountability from the doctor. This does not constitute accountability from a patient perspective. Process outcomes do not equate to a personal acknowledgement of error from the doctor, indeed the nature of the process is to deflect from the personal, the emotional, towards the analytic and considered aspect of an AE. Processes are simply processes, and do not provide healing for the hurt experienced by patients following an AE, which is felt as a betrayal of trust by doctors and the hospital system. Patients remained angry and frustrated. Anger is the default response when there has not been acknowledgment of the patient as a person who has been harmed, albeit unwittingly, by the doctor concerned.

**Chapter 9: Case Illustrations of the 4A Model**

In this Chapter, I describe the way in which 3 people’s lives were impacted and changed by their AE as illustrative of a broader AE community. Margaret, Carolyn and Anthony cross over all four As of acknowledgement, accountability and apology and anger: their concerns are overlapping though the focus of each participant can be discerned by the titles I use for their stories. The lack of acknowledgement of medical error by a doctor left these participants sceptical about the medical profession, so much so that Margaret and Carolyn made life changing decisions about future family options. Anthony still awaits an apology from his chosen surgeon. I conclude this Chapter with the outliers, the participants who did not “fit” the 4A Model, and I propose reasons why that may have been the case on the basis of the individuality and life experience of the participants leading up to their hospital admission.

**Chapter 10: Conclusions and Recommendations**

In this Chapter, I present my answers to the research question in terms of 3 key
conclusions. Firstly, I have come to the view that an AE is not simply something that happens during a hospital stay. It is not an incident; an AE can be life changing and the repercussions life-long. The response of the doctor to an AE is critical. Acknowledging an AE, an error, can be healing for the patient: denying an AE can be counter-productive for both the patient and the doctor. Secondly, the patient focus in the context of an AE is primarily on their perceived relationship with a doctor, and acknowledgement of themselves by the treating doctor, who is prepared to honestly and openly discuss the patient’s condition. To be meaningful for the patient, more than a formal process of apology is required, rather a personal exchange, each respectful, one to the other. Patients want to know the details of and causes of their AE, but it has to come from the doctor concerned, the treating doctor who accepts responsibility. On this basis, my practical third conclusion is that an OD protocol does not meet the needs of patients because it does not necessarily involve the doctor concerned or address the patient’s understanding of the meaning of the AE. This is important. Patients want acknowledgement and in a personal way.

Finally, I offer recommendations for training of medical students, junior and senior doctors about responses to patients who have suffered an AE, in the knowledge that medical errors happen, that patients can be forgiving if given the opportunity by doctors to do so: the existential and relational concerns of patients can be met. Doctors do not need to be afraid of patients and legal actions, if they talk to their patients in an open and honest way, a personal exchange that includes an acknowledgement that things didn’t go according to plan in the surgical procedure and that he/she the doctor takes responsibility for the error, because it occurred under his/her watch, can be a healing outcome for both.

I conclude with some personal reflections on my research journey and findings.
Chapter 2:

Adverse events in the context of the Western Medical Model

Introduction

The purpose of this Chapter is to introduce the concept of AEs to the reader, framed within a Western medical model of health care and delivery. There have been many studies undertaken about AEs (Gray, 2003). I begin with a definition of AEs, and how AEs came to public attention and why. I continue with a discussion as to how AEs have been responded to and why by doctors and hospital institutions. Patient safety concerns and ways to address AEs, in the form of an “open disclosure protocol” are discussed. In Chapter 3 I discuss the doctor and hospital relationship, and the reasons why AEs have been difficult to discuss and handle, and in Chapter 4 I discuss the perspective of the patient, of being a patient, before having to contend with an AE and its aftermath.

Definition of an AE

An AE is an event that happens within a life context, and in this study within a public hospital environment and by a patient who has entered into care. De Vries defines an AE as an unintended injury or complication resulting in prolonged hospital stay, disability at the time of discharge or death, and caused by healthcare management rather than the patient’s underlying disease process (De Vries, 2008). This definition is current, and entirely consistent with that of previous studies of AE’s, the studies that sparked an interest and concern about AEs by drawing attention to the statistics of AEs: (Brennan T.A, Leape,L.L, Laird, N.M, Hebert,L, Localio, A.R, Lawthers, A.G, Newhouse, J.P, Weller, P.C, and Hiatt, H.H, Harvard Medical Practice Study 1991) and (Wilson R, Runciman.W.B, Gibbert,R.W,Harrison,B.T, NewbyL and Hamilton, J.D, 1995 The
Australian Quality and Health Study, 1995). An AE has been statistically defined, medically determined, but not patient defined or understood. What constitutes an AE may depend on one's perspective, what is experienced as an AE may not necessarily be considered to be one by the doctor involved. The word “patient” derives from the Latin word “patiens”, meaning to suffer. The unique nature of the Doctor/Patient relationship means that the impact of an AE may be especially powerful, as the patient has been harmed by the very person invested with a high degree of trust (Vincent, 2002). Within the medical lexicon an AE, is a term used to describe an unintended harm caused to a patient as a result of the health care received during hospital stay (Wilson et.al, 1995); (De Vries, 2008).

**Historical Background to AE literature**

AEs came to public attention with the release of the Institute of Medicine report (IOM), entitled “To Err is Human” in Washington 1999 with the imprimatur of then President Bill Clinton. It took a high profile report such as to “To Err is Human” to capture government and public attention to the data that had been gathering for years. The report spoke of the magnitude of AEs, as the 8th largest cause of death in the US Hospital system, raising concerns for patient safety as well as complications for the public health system costs and budgets as patients took legal action following a perceived AE. This report gave rise to the identification of AEs as an epidemic in health care costs and patient safety statistics in the United States and Australia. This was a landmark study because it captured the attention of Governments about costs to public health systems because of medical errors. Earlier studies had documented the prevalence of AEs in hospital systems. Data began to emerge with the 1984 publication in the United States of the Harvard Medical Practice Study (HMPS) (Brennan, Leape, Laird et al, 1991). HMPS examined retrospectively 30,195 randomly selected records from 51 hospitals in New York State. The HMPS reported that AEs occurred in 3.7% of hospitalisations, of which 28% were considered the result of negligent care. The Quality in Australian Healthcare Study (QAHS, 1995) sought to determine the proportion of admissions that were associated with an AE in Australian hospitals. The QAHS recruited 8 hospitals in South Australia and 23 hospitals in New South Wales including major teaching hospitals, rural,
district, and private hospitals. The QAHS Study found that 16.6% of the 14,179 hospital admissions studied were associated with an AE, noting that over half of these were considered preventable, 13.7% giving rise to a permanent disability for the patient, and in 4.9% of cases the patient died (Wilson et al., 1995). In a follow-up study, Dr. Ross Wilson, the first author of QAHS, reported that “cognitive failure” by clinicians appeared to have a role in 57% of all the causes of AEs judged to have had high preventability and which led to a permanent disability (Wilson, Harrison, and Gibberd, 1999). The representative “Doctor” in the context of the Australian AE study was perceived to have had difficulties with technical performance, had failed to decide or act on available information, failed to investigate or consult, lacked care and/or failed to attend as required.

A study of the incidence and nature of surgical AEs was conducted by Gawande et al. in Colorado and Utah in 1992, but published in 1999 after the Harvard Medical Practice Study of 1994 and coinciding with the IOM Report. In the findings, Gawande noted a shift in emphasis away from one of medical error to a concern about patient safety. The hallmark of the IOM Report was encapsulated in its title “To Err is Human”, which sought to normalize medical errors or rather acknowledge them as a fact of clinical practice and hospital procedures. By documenting shocking AE statistics, an underlying purpose of the IOM Report was to change medical culture so that the “blame and shame” of colleagues who had erred in treatment procedures, as discussed in the next Chapter, did not prevail, assuming of course, that the errors were not blameworthy. Rosenthal distinguished between medical errors and blameworthy AEs and how they have been typically addressed within the medical collegiate (Rosenthal, 1995).

The IOM Report shifted the focus away from individual doctors and individual medical error to a “systems approach” view of medical error which meant that there were many contributing factors to an AE and an individual doctor should not be held responsible for an error, and that others also on his or her watch may have contributed towards the error. Whilst patient safety and associated statistics were headline issues, in reports of AEs, there was also an underlying concern about the cost of AEs to public health systems and to doctors in particular through increased medical indemnity insurance premiums which
occurred in an Australian context (Skene, 2004) and resulted in legislative interventions to cap patient compensation claims following an AE, with thresholds established in Victoria according to levels of patient impairment following an AE (Skene, 2004). A special case, that of patient, Calandre Simpson, whose future care costs were going to be substantial, resulted in a significant damages payment (Skene, 2004) and mobilised the medical defence agencies. The cost implications of AEs to public health care budgets has been a central focus, if not viewed through a litigious lens necessarily, but simply in terms of the extra costs associated with an AE (Ehsani et al., 2006) often involving extended length of hospital stays, which in turn can give rise to further AEs (Andrews and Stocking, 1997).

The re-conceptualisation of adverse events as a “systems” problem

James Reason’s work on human error shaped the systems analysis approach that has been adopted in Australia, the U.S and the U.K (Reason, 2000). Reason argued that as humans are fallible, errors are to be expected but that the conditions under which people work could be changed in ways that could make a difference to the overall incidence of AEs (Reason, 2000). Drawing on organisational theory, and by reference to high risk industries such as aviation and nuclear energy, Reason suggested that the hospital setting required features to be built into the system that provided constant reminders to staff to be on the alert for potential errors: See (Department of Human Services, Improving Patient Safety in Victorian Hospitals, September 2000). The Reason analysis shifted the focus away from individual medical error, and by so doing made the discussion of error possible and plausible. Whilst Hospital reporting mechanisms have been systematized and improved, it is not clear that the systems approach has improved patient outcomes, in terms of the incidence of AEs.

Identifying and reporting of adverse events

Medical culture, including the self-regulatory nature of the profession, and a fear of being sued are often mentioned as barriers to health care professionals
admitting to mistakes in the treatment of patients in a non-confidential way (Health Report/Radio National “Should Doctors and Nurses admit their mistakes”, Monday 15 July 2002 and Department of Human Services, Improving Patient Safety in Victorian Hospitals, September 2000). Freidson (1975) noted “etiquette” as a cultural norm in discussions by doctors about other doctors who may have been seen to be under-performing or making mistakes. Rosenthal (1995) elaborated and identified a 3 stage process of quiet chats, escalating in intensity, by which problem doctors were dealt with by colleagues. In a cross-sectional study of operating theatre and intensive care unit staff and airline cockpit crews concerning attitudes to error, stress and teamwork, the medical staff admitted that discussing mistakes was difficult and generally not well handled (Helmreich et.al, 2000).

Recognition of these impediments, and their potential impact in terms of patient safety, informed the decision to establish the Australian Council for Safety and Quality in Health Care (ACQHS) in 1999. Its charter was to “promote changes in the culture in which health professionals work from one of ‘judgement and blame’ to one of ‘learning for quality improvement’ (Report to the Australian Health Minister’s Conference, July 2000).

The reporting of AEs has been unreliable, as is suggested by the variance of between 3% and 18% referred to above. Whilst Hospital Protocols have been in place, the relative autonomy of medical practitioners within that setting has meant that there have been difficulties in developing a uniform approach as to what constitutes an AE.

In order to reduce the subjectivity of reporting of AEs, there is in place a 3 tiered system of Protocols in Victorian public hospitals. Incident reporting is the first step and refers to a sheet that is meant to be filled out and filed where there has been an error of relatively minor consequences. Slips, falls, patient complaints are often in this category. Nurses are the most likely health professionals to attend to this administrative function. At the next level, there is a notification procedure to a Patient Safety officer where it is considered that the basis for a legal claim against the Hospital may exist. These are voluntary reporting mechanisms, and the extent to which they are observed is likely to depend on the organisational
culture of the Hospital, and more specifically the approach adopted by the senior clinicians of individual medical units. In the case of "sentinel", or catastrophic events, there is a mandatory reporting requirement to the Department of Human Services, where a central registry is kept. Notification is sent to all public hospitals of all sentinel events.


Similar initiatives were taking place elsewhere. In the United States, the publication of “To Err is Human: Building a Safer Health System” captured attention with the statement that medical errors ranked as the eighth leading cause of death in that country. The Report noted that the traditional way of dealing with medical error being the “naming, blaming and shaming” of individual practitioners had led to a conspiracy of silence about patient safety issues (Institute of Medicine Report, 1999). As a result of the Report, a Task-Force was established with a stated objective of reducing the incidence of AEs by 50% within 5 years.

In the United Kingdom, The Bristol Royal Infirmary Inquiry into deaths of paediatric cardiac surgical patients found that a “club culture” where there was an imbalance of power, with too much control in the hands of a few had led to around one-third of all the children who underwent open-heart surgery receiving less than adequate care. The Inquiry recommended, inter alia, that the National Health System of the future must have a culture of openness and accountability: “when things go wrong hospitals and healthcare professionals have a duty of candour: to be open and honest. Not only does this show respect to patients; an error, once acknowledged, also allows lessons to be learned”. The National Patient Safety Agency was established in July 2001 “to co-ordinate the efforts of the entire country to report, and more importantly to learn from, patient safety incidents occurring in NHS-funded care”. The inaugural Chair, Professor Rory Shaw, described the role of NPSA as “to go and look for AEs, for near misses, and ask not who did it, but why it happened and what were the root causes” (Department of Health Media Centre UK, Press Release 13 June 2000). As part of the campaign to create a more open culture, senior medical figures in the
United Kingdom were encouraged to “own up” to past mistakes as a way to encourage younger doctors to report incidents.

**Disclosure of medical error as a “risk management” tool: The emergence of open disclosure**

The Veterans Affairs Medical Centre in Lexington, Kentucky in the United States adopted an approach of proactive and full disclosure of medical error to patients and/or families with financial compensation packages offered immediately. It was considered that AEs were not dissimilar to divorce proceedings in terms of an apparent betrayal of trust and that litigation involving the Hospital, Doctor and the patient may be unhelpful to all concerned (Kraman, 1999). Medical liability payouts decreased as a result of the Lexington OD approach. The extent to which this was due to the disclosure of error and expression of regret to patients and their families, or the immediate offer of financial compensation in a lawyer-free environment is less clear. However, it was a ground-breaking initiative that advocated complete honesty with patients involving a timely and OD of medical error. (See also: Liang, 2002; Vincent and Coulter, 2002; Philip, 2001).

The discussion about the merits of OD of medical error has typically been framed in a practical way: as a risk management tool referred to above, or posed as a question in terms of what patients want to know at a particular point of time (Hopgood, 2002). There has been less attention to situating OD practice within the medical and ethical framework of “do no harm”.

**Open Disclosure Standard Introduced in Australia**

The Lexington model informed the development of an OD Standard in Australia. In July 2003, an Australian Standard for disclosure following an AE was introduced under the auspices of the Australian Council for Safety and Quality in Health Care. The Standard provided a framework for open communication following an AE in public and private hospitals.
The principles to be applied included:
- Openness and timeliness of communications;
- Acknowledgement of error to the patient;
- Expression of regret to the patient/family;
- Recognition of the reasonable expectations of the patient/family.

The Open Disclosure Standard recommended an expression of regret as distinct from an apology (Open Disclosure Standard; Australian Council for Safety and Quality in Health Care; July 2003). The difference between the two may seem semantic but it is actually stark and driven by legal concerns. An expression of regret is simply that: it does not convey any personal sense of responsibility for the harm caused. The Standard also recommended that the person disclosing should be “known to the patient” but it need not be the clinician concerned. Further, it stated that junior clinical staff or those in training should not be involved in the disclosure process (Open Disclosure Standard; Section 10.4.5) irrespective of whether they had been involved in the AE. The Australian Open Disclosure Framework was subsequently adopted (Australian Commission on Safety and Quality in Health Care, 2013).

**Summary of Chapter**

In this Chapter, I have given an account of the history of OD in Australia. OD was conceived of as a risk management strategy for hospitals and doctors, following the identification of AEs as a problem within the Australian hospital system, in the light of the published findings from the US identifying an alarming percentage of hospital patients who suffered an AE during their hospital stay, which subsequently involved legal action. An OD began as a strategy and a process for managing risk to hospital institutions and doctors by attempting to assuage patient concerns or anger about an AE, rather than an intervention aimed at meeting patient’s needs after an AE. An OD is not a process designed to meet patient needs, following an AE, because the other main protagonist, the doctor, is not required to be present or acknowledge the patient as a person who has been harmed, albeit unintentionally, by their medical care. In Chapters 6 through to 9, I review an AE and an OD process through the lens of the patient.
Chapter 3:
Hospitals and Doctors: An AE as a medico-legal construct

Introduction

As noted earlier, there are different perspectives about an AE, each operating within a particular framework of understanding and expectations. Public hospitals operate within a governmental and legal framework of rules and regulations, commercial dictates and constraints. Medical practitioners working within the public hospital system are expected to observe both the hospital protocols as well as those of their respective medical collegiate. Patients admitted to a public hospital have expectations of good treatment and care. AE’s happen within a social setting of rules, regulations, protocols, trust and expectations, which may not always be in alignment, and can end in conflict as between hospitals, doctors and patients respectively. They are all in the mix together.

The literature that could be useful in understanding an AE experience falls into a number of categories: I begin broadly in this Chapter, and then narrow my focus to patients in the next Chapter. The evolution of the institution that is the modern Western hospital is my starting point. The hospital deserves acknowledgement in its own right. The hospital is the setting in which, historically, the sick or infirm have been received for care and treatment; where medical trainees have and continue to learn their craft through observation and trial (Foucault, 1973; Turner, 1995); and as a result of experiential learning the practice of medicine successfully laid claim to professional status (Freidson, 1970, p.21). In the 20th and 21st Centuries, the hospital is also the site where AEs have been recognised. AE’s have always occurred: they are not a new phenomenon, but now constitute a label with legal consequences. The hospital is the main site where the issue of medical liability arises, creating a triangulation of concerns and tensions: public
hospitals and their insurer; doctors and their medical indemnity insurers; and the patients who suffer AEs

I continue with a discussion of the body of literature around the culture of medicine and the “formation” of doctors within the hospital setting as an essential part of clinical training. Experiential learning, peer review and senior doctor/consultant supervision are all factors contributing towards the development of an individual as a member of the medical collegiate. The socially sanctioned privileges conferred on the medical profession are considerable, and so too are the associated societal expectations of medical care delivery. When medical care is felt by the patient as having failed, the perspectives of patients and clinicians may differ as to the seriousness of the AE and its consequences for the patient.


**The Hospital as a Public Institution and Site of Medical Education**

The hospital has evolved over centuries reflecting the nature and preoccupations of the society within which it was situated at any given point in time (Rosen, 1963, p.2). It has its origins in medieval times where monks, in the Christian tradition of charity towards one neighbour, offered care and respite for the ill, the destitute and a safe haven for pilgrims (Rosen, 1963). The hospital began its role as a clinic in 17th Century Holland with bedside training and the dissection of cadavers (Rosen, 1963, p.15). Foucault claimed that it was the reorganisation of the hospital field and its designation as the principal site of medical learning and credentialing in Post Revolutionary France that led to the development of a
distinctive “medical gaze” (Foucault, 1973, p.196) or rather, the clinical observation of a patient in the controlled setting of the hospital. The “gaze” is discussed in the next section on the enculturation of doctors.

Scientifically based medicine flourished in a hospital setting as the causes of disease became known and technological developments were made such as those relating to anaesthesia and asepsis (Freidson, 1970, p.16). Charitable, or voluntary, hospitals sprang up in the U.K, from the 17th century onwards, largely as a result of private initiative and philanthropy (Turner, 1995, p.160). Public confidence in hospitals grew as mortality and morbidity rates declined, and a new hospital clientele group emerged in the U.K being middle class, paying patients (Turner, 1995. p.160). New specialty hospitals were constructed, funded by benefactors, which in turn created more professional opportunities for medical practitioners. Hospitals in the U.K began a gradual transition from Church based to more community, secular institutions and in the 18th and 19th centuries, local government authorities began to play a role in funding and running hospitals (Rosen, 1963, p.19,22).

Doctors became essential to hospitals and conversely, the hospital became the principal site for teaching clinical medicine (Rosen, 1963, p.31). As a result, a virtual monopoly was granted to doctors over health care provision, laying the groundwork for the claim that the practice of medicine was a “profession” (Freidson, 1970, p.21). Witz observed that the focus on hospital based health care provision caused a structural shift in the delivery of care by removing it from home and community settings, largely the domain of women, to an institutional one dominated by men (Witz,1992, p.80).

Public hospitals in Victoria were established in the U.K tradition of benefaction and specialities. Universal access to public hospitals occurred through a spread of hospital locations in Victoria from the 1950s onwards (Victoria’s Health to 2050, Department of Health and Community Services, 1995, p.3). During this time, doctors were highly influential, if not pre-eminent, in hospitals which were typically overseen by Boards of Governors or Trustees usually serving in an honorary capacity and drawn from members of the local community. There was a sense of civic pride and ownership of the local hospital which contributed to a
benign, if not deferential, attitude to the medical staff: it was a golden age for the profession.

**A Changing Hospital Environment: Implications for Doctors**

The benefits of co-location as between doctors and the hospitals that they served may have been somewhat offset by an organisational structure that required clinicians to co-exist with management, a situation that Rosen speculated may have been distasteful to some if it was understood as undermining their professional autonomy (Rosen, 1963, p.31), potentially by introducing new lines of accountability. Freidson (1970, p.137) and Goss (1963, p.176) have written of the high value doctors place on autonomy and independence in the discharge of their professional duties. Turner suggests that doctors retain considerable power in terms of decisions about patient treatment options (Turner, 1995, p.156) and that a duel hospital authority structure exists between management and doctors. However, with the introduction of Case mix funding by the Victorian Government in the 1993-1994 budget, the hospital environment became more complex with a greater emphasis on accountability of doctors to management. The Case mix formula involved hospitals being paid a set amount for procedures performed, measured against length of inpatient stay, that is, an activity based efficiency criteria designed to maximize throughput of patients with acute needs. The mechanism required adjustment over time (Interim Report, Metropolitan Hospitals Planning Board Report 1995, p.7) but it highlighted performance differences between hospitals. The role of the hospital as a community institution was questioned and overtaken by the major re-organisation of hospitals that took place in Victoria in 1995. The then Government considered that the existing hospital configuration constituted an impediment to the health care system: too many “individually run” hospitals (Victoria’s Health to 2050 p.vii) and forecast that by 2050 hospitals would have a “diminished role” in the health system (Victoria’s Health to 2050, Department of Health and Community Services 1995, p25). Hospital Networks were created, being amalgamations of hospitals within a geographic area, and offering a wide range of health care services. A new governance structure was put in place with Boards of Directors appointed by the Minister of Health on the advice of the
Department of Human Services on a paid rather than voluntary basis. Under the
Health Services (Metropolitan Hospitals) Act 1995 the new Boards were
charged with a range of responsibilities including the establishment of an
organisational structure for the hospital; appointment of the Chief Executive
Officer and senior management staff; development of a business plan; and to
“develop plans, strategies and budgets to ensure the provision of health services
by the hospital and the long term financial viability of the hospital” (Health
Services (Metropolitan Hospitals) Act 1995, Act No. 46/1995 Section 40D). The
emphasis was on financial oversight and management with the expectation that
Hospital Networks would be run as corporate enterprises and that much
“hospital” work could and should be done in local, less expensive settings
(Presentation to Hospital Network Boards by Dr John Paterson, Health and
Community Services, 25 July 1995 p.13). Without any sense of irony, the new
Networks were charged with focussing “on people- not institutions or systems”
(Implementation and Resource Kit for Southern Health Care Network, supplied
by the Melbourne Hospitals Planning Board, August 1995, p.1).

The changes that were taking place at a governance level had implications for
doctors. Doctors became accountable to Hospital management and Boards of
Directors, not individually, but as part of the speciality groups they represented,
for service delivery and performance against budget. Clinical Service Agreements
were entered into “in relation to service provision and performance in terms of
throughput, expenditure, key performance indicators and quality management”
(Operational Plan and Clinical Service Agreements 1997-1998, Southern Health
Care Network as representative of Network Agreements). A change of
Government in Victoria in 1999 ushered in another re-organisation of the public
hospital system. The 7 Health Care Networks were disaggregated and replaced
by 12 Metropolitan Health Services (Ministerial Review of Health Care Networks
Final Report May 2000, p.2) in order to address the “cash crisis” (p.5). The extent
to which doctors were challenged by the changes to the way hospitals were
organised and costs reigned in has not been documented. However, by analogy,
Bock’s work on doctors in the U.S hospital system is informative. In the second
edition of “Forgive and Remember” (2003), Bosky reflected on the changes that
he had perceived since his original research was published in 1979. In the
intervening period a system of managed care had been introduced in the U.S. This involved, as with the Victorian Government initiatives, the adoption of corporate values regarding the efficient use of hospital resources, achieved in part by centralized decision making far from the bedside of the patient (Bosk, 2003, p.244). In the 1970s the mobilisation of resources was at the discretion and on the authority of senior doctors (Bosk, 2003). Bosk concluded that the power and authority of doctors, the clinical individualism he had observed and accepted as the norm in 1979 (2003, p.242), had been significantly undermined (Bosk, 2003, p.239).

In the UK, the British Medical Association reported that the significant changes taking place in the National Health Service was a source of stress and uncertainty for doctors working in the system who felt their role as clinicians increasingly undermined by managers (Dillner, 1992).

**Further Constraints on Medical Autonomy**

In the same time frame, a debate began about the role of the patient in medical decision making. Patient autonomy was defined as a key ethical principle and enforced by law (Skene, 2004). Doctors had to ensure that patients were fully informed about a proposed medical intervention and made, either on their own behalf or by proxy, a voluntary choice to proceed. The doctor patient relationship, traditionally characterised as paternalistic, was reviewed and other potential models discussed (Emmanuel and Emmanuel, 1999, p.67). Strong paternalism was deemed no longer appropriate and a different way of thinking and behaving on the part of doctors was encouraged, such that they worked together with patients as “true partners” (BMJ,2003,p.326). The autonomy of medical decision making has been further circumscribed by the emergence of clinical bioethics as a discipline, the role of which is to consider, discuss and evaluate the ethical and moral challenges that arise in the practice of medicine. Ethical questions were once regarded as “sinkholes” in the sense that the discussions could be time-consuming with no clear cut resolution, distracting doctors from a more productive action orientated treatment programme (Bosk, 2003, p.248). Doctors now have to be prepared to engage in a conversation with other professionals.
about treatment options, once their sole prerogative, including what constitutes the best interests of the patient (Bosk, 2003, p.247).

Media coverage of AEs, including the publication of sentinel events that have occurred in Victorian public hospitals in the preceding 12 month period, resulted in a more informed general public, arguably inclining them to be more sceptical and questioning of doctors and their performance (Cruess and Cruess, 2002, p.210). This is a further constraint on the autonomy of doctors, who today could be considered to have less power but more accountability.

**Hospital Based Training and the Enculturation of Medicine**

The culture of medicine, that is the Western medical model, has evolved over time as practice became a profession located in the hospital. The literature suggests that there are distinctive features of a medical perspective which are culturally acquired, being the way in which patients are regarded and engaged with, and the way in which medical error is assessed, evaluated and dealt with by colleagues. Medical students and junior doctors typically learn how to become fully accredited doctors in the clinical and experiential setting of a tertiary teaching hospital which works to enhance the academic learning by offering students the opportunity to observe and engage with real patients (Foucault, M, trans. 1973, p.109). Modern medical schools also offer placement opportunities that extend beyond the tertiary hospital to include other settings such as community health care centres, and rural practices, which are designed to broaden the learning experience of trainee doctors beyond the tertiary hospital and expand their perception of the health care needs of the community more broadly. In New Zealand, for example, a programme of “rural immersion” has been designed to expose medical students to rural medical practice which includes a comprehensive range of health care needs, including palliative care, nursing home visits, and emergencies as presenting to the local clinic. Experiential learning which is to say learning on the job has been the feature of the programme (Mayer and Renouf, 2016). Dr Mayer’s work builds on, and is consistent with, earlier research suggesting that experiential learning is the key
to developing a trainee doctor’s sensibility, intuition, and gaze.

At the heart of the hospital based training system is what Foucault described as a “medical gaze”, being a way of viewing a patient as a human body with a disease, a the on the pathology rather than the person. The hospital patient is also a site of learning, and the symptoms capable of generalisation. The uniqueness of illness to n individual is not the primary concern (Foucault, 1973). Freidson (1961, pp. 175-176) observed that the routine of medical practice required a detached view and that each patient constituted a “case” reducing individual instances to a routine, the ordinary, and an economic transaction between doctor and patient. Good commented that medicine privileges the biological and scientific over the existential and described the writing up of a case by junior doctors not so much as an exercise in interviewing patients, rather about presenting them to peers and superiors (Good 1994, p.70-80). It was a contest he suggested, and learning to “play the game” and win the respect of others was also how del Vecchio Good described the junior doctor experience. It required a demonstration of competence principally defined in terms of “medical sleuthing” and diagnostic skills (del Vecchio Good,1999, p.5) on display to a peer and senior medical group. In a study of junior doctors in a Victorian public hospital, it was noted that an intern or resident takes part in daily ward rounds with the registrar and the entire team comes together 3 times a week for the consultant’s ward rounds. During these rounds the intern or resident is expected to present concisely a patient’s history and clinical details to the other doctors. The consultant questions the junior doctor potentially exposing ignorance or incompetence. This is considered a particularly stressful time for junior doctors (Mc Dougall, 2009, p.73). Helman argued that the medical profession was quintessentially “physician centred” and that the engagement with hospital patients was marked by distance, formality and the use of medical terms that were not likely to be easily understood by recipients (Helman, 1990, p.69-70). The medical, rational scientific perspective, or gaze, could reduce human beings to a series of “abnormal physiological parameters” (Helman, 1990, p.86) with little regard to the existential pain of the patient.

The privilege of a high level of autonomy and the right to self-regulate are distinguishing features of professional status and they, in turn, inform and shape
the perspective and behaviours of new medical recruits. Freidson (1961, p137) labelled socially sanctioned autonomy as the ultimate test of professional status: it was a demonstration of mastery of a complex body of knowledge and skills such that a non professional would be ill-equipped to evaluate or regulate proper performance (Freidson, 1967). In addition, the medical profession laid claim to the highest ethical and altruistic standards asserting a capacity to work without external supervision in the public good. In return for these assurances the medical profession was granted the twin privileges of a high level of autonomy, both individually and as a profession, and the right to self-regulate. In the preceding section I described how a changing hospital environment had circumscribed the autonomy of doctors. The right to self regulate, and to discipline colleagues within the medical collegiate framework remains.

The practical and moral licensing of practitioners to provide good medical practice is a critical self regulatory function underpinning the status of the profession as a whole. The way in which medical errors are discerned and problem colleagues dealt with is within the remit of the profession until such time that it erupts into the public arena by formal complaints made or actions taken by patients. Within medical culture, medical error can be normalized or distinguished depending on the perspective of fellow practitioners about how they perceive the situation and the error. This does mean that the perspectives of the patient and doctor may differ as to what constitutes a medical error or AE and its severity. A doctor may consider that if the patient has come to no ultimate harm, such as in the case of remedial surgery to address an error made in the first procedure, for example wrong sided surgery or the insertion of the wrong prosthesis that an AE has not occurred. A patient on the other hand may regard an unnecessary second operation as an AE causing personal anguish. Junior doctors who witness these mishaps may be reluctant to speak up for fear of repercussions for their career prospects if they fall out of favour with senior medical staff (Mc Dougall, 2009). The expectations of etiquette, as between medical professionals, is another acquired cultural norm instilling the need for considerable discernment and discussion as to what constitutes a medical error, adopting a medical gaze.

Sociologists have observed that a line is drawn between what Freidson called normal errors and glaring mistakes (Friedson, 1975, p136) and Bosk described
as blameless and blameworthy (Bosk, 2003, p.xix). Freidson suggests that this is a more powerful cultural norm within the medical profession than accountability per se (Freidson, 1975, p.242; Del Vecchio Good, 1995, p.5). Rosenthal noted that medical mishaps or mistakes do not typically elicit collegial sanctions either formal or informal (Rosenthal, 1995, p.125). In a UK context, Rosenthal summarized the self-regulatory framework as a 5 step process with gradations of severity and implications. Beginning with what Rosenthal called “a quiet chat”, or personal persuasion, through to protective support before quasi formal mechanisms come into play. The disciplinary protocols are discrete and protective of the problem clinician up until the time that such support can no longer be sustained on the evidence (Rosenthal, 1995, pp 54-63). The privilege of the profession means that doctors determine which medical errors are held to account: which interventions are to be regarded as routine errors of medical practice, and which are egregious from a clinical perspective (Rosenthal, 1995, p. 125). Collegiality does not necessarily constitute collusion regarding medical error, but Foucault’s “medical gaze” suggests a lens that has both an outward and inward looking focus: the patient as object of observation by doctors with the aim of healing, and the medical profession looking to each other as a collegiate when mistakes happen. Cruess asked the question as to whether the medical profession has from time to time placed its own interests above that of the public interest (Cruess et.al, 2002, p.210) with associated implications for reputation damage. An example of this was documented in the findings of the Bristol Royal Infirmary Inquiry in the UK, revealing as the Inquiry found to be a masculine “club culture” which was protective of it’s own. The surgical team at the Hospital had taken no action in the face of unusual paediatric mortality rates was the finding of the Inquiry (Bristol Royal Infirmary Inquiry; The inquiry into the management of care of children receiving complex heart surgery 1984-1995. London: Stationery Office; 2001). Katz, P, 1999 identified a particular culture amongst surgeons in the US being confident, emboldened and action orientated. Cassell used the words “control and certitude” as synonymous with “paranoia” to describe the surgical medical mind set (Cassell, J. 1987, p.236).

The influence of the institutional culture on the preparedness of doctors to own up to medical error also needs to be taken into account. Factors such as the
perceived error tolerance, combined with a supportive environment may enable
and empower doctors (Fein, 2005, p.489).

**Conclusion**

In this Chapter I have documented the historical and continuing symbiotic
relationship between the hospital and the medical profession. I have described
the changes that have taken place in hospitals as a result of the introduction of
corporate values and associated commercial imperatives, including the profound
impact on doctors as their autonomy within the hospital diminished but their
accountability to managers and Boards of Directors rose exponentially.
Essentially this has represented a transition from the traditional model of
doctoring described by Talcott Parsons (Parsons, 1978) which also assumed a
way of being a patient, which is to say that the doctor in charge knows best.
Doctors in the public health system today have the same range of responsibilities
to their patients, associated with being a doctor, but an extended range of
accountabilities beyond the medical collegiate, to Hospital managers and
administrators. I have also examined the acquired nature of medical cultural
norms which occur in the public hospital training setting as regards how the
patient is regarded as a source of medical observation and information for trainee
doctors. I considered the privilege of self regulation and the way in which doctors
view medical error, often differently from a patient perspective. Escalating health
care costs in Western countries in the 20th and 21st centuries, referred to in
Chapter 2, including those associated with medical errors, has altered the
balance of power as between doctors and the hospital environment in which they
work. Doctors, with the aid of benefactors and supporters, used to be in charge of
public hospitals. By way of example, Doctors John Singleton and William Smith
were responsible for the establishment of the Royal Children’s Hospital and
without commitment and community support an important institution would not
have emerged and survived. A similar story of doctor initiative and benefaction
underpins the histories of the Royal Melbourne and Royal Women's Hospitals.

However, doctors working within the hospital environment today face
complexities associated with a working environment within which Government
funding priorities change, influencing hospital programmes and resource allocations. The environment in which doctors now work is one similar to that of a service provider, a contractor, accountable to management, as well as peers. Increased scrutiny on doctors has shone a light on medical error and AEs, which have always existed, but have become more complicated issues for both doctors and patients. The direct relationship and explanation of medical issues as between doctor and patient has an overlay of legal implications. It is not easy being a doctor in the 21st century.
Chapter 4:

Patienthood

Introduction

The word “patient” is derived from the Latin word “patiens” meaning to endure, bear or suffer and, within the Western medical model lexicon, is a term used to describe a person in poor health who requires medical treatment often occasioning a stay in hospital. Expectation and hope is what a patient typically brings to a medical encounter and hospital admission, and suffering is what some patients endure afterwards, not only because of illness, but because of a medical error or mishap. Suffering from an AE is pain unnecessarily caused, and of a different kind, being a mix of physical and psychological harm, challenging a patient’s socially constructed world view of trust in doctors and the hospital “system”.

In Chapter 2, I gave an account of the way in which AEs came to public attention when international and national studies revealed the frequency with which patients were unintentionally harmed during their hospital stay. The statistics were alarming in a patient safety sense, but also for health care budgets. In Chapter 3, I documented the history of the hospital as the site of the establishment of medicine as a profession: intertwined and interdependent. Hospitals needed doctors to attend to patients and trainee doctors needed sites in which to practice and learn skills under the supervision of more learned colleagues. In Chapter 3, I also discussed the way in which medical culture had contributed towards AEs in terms of a reluctance to report, or under-report, medical errors in the context of an expectation of mutual discretion and collegiate etiquette, and personal fears of professional repercussions if they spoke out within the hospital environment in which they worked (The Bristol Royal Infirmary Inquiry: the issue explained.  http://theguardian.com/society/2002/jan/17/5).

In this Chapter, I consider an AE within the broader context of the patient perspective of illness and health care. The literature about patients and AE’s
has been framed in the context of why people sue following an AE, their underlying motivations and perceived outcomes (Vincent, 1994). It has also been considered from the perspective of an OD process and the best way to deliver an OD protocol (Iedema, 2011). The aforementioned are important studies because they provide bookends, as it were, for the reasons why legal actions led to OD policies and then the perceived effectiveness of the implemented OD protocols (See also Mazor, 2013). The studies are limited though because they do not address the impact of AEs, more broadly, and consider the wider effects of the AE on the patient’s life and expectations, and in particular, how patients make sense of the experience, and the meaning they ascribe to it over time. This aspect of the patient AE experience has not been previously documented. There has been no change in terms of patient expectations of doctors, as reported in this study.

This Chapter provides the four key elements that set the theoretical framework that informs my thesis. They are:-

1. Patienthood as a social role, which has a passive or powerless role;

2. The patient experience of illness, accompanied by a loss of ontological security with hospital admission, and subsequent events leading to a loss of trust;

3. The different perspective between doctors and patients as to what constitutes illness, an AE, and suffering; and

4. The desire of participants to make meaning out of their suffering, for themselves and for others.

Theoretical Framework

There are 4 key elements of the theoretical framework that underpins my thesis. These represent the stages of a patient journey and response to an AE. They are:

1. Becoming a patient

Whether for emergency or elective procedures, the process of becoming a patient in a hospital setting is widely recognised in the literature as an often confronting and transformative experience (Casell,E, 1985 and 2004, Frank, A 1995). Casell and Frank have written about their “ill” selves, from the privileged position of being members of the medical profession when they became ill. Whilst this gave both men knowledge and understanding of their medical conditions, it did not change the fact that once they were hospital patients, they were reliant upon others for their well-being and care, and felt vulnerable.

Patienthood is a levelling experience. There is an assumed passive role
associated with being a hospital patient because “others” who know more, supposedly, are in positions of authority and control over one’s health care. A patient has to trust in the people in charge, there is no other option, but there is a fragility associated with the delivery up of oneself into the hospital system (Mechanic, 1996). There is a socially constructed role differentiation, and power position, between patients and doctors, which allows the hospital system to work, but can lead to anger and frustration when things go awry from a patient perspective.

2. The patient experience of illness

A number of key studies have identified confusion and loss of trust as part of the patient experience. I have referred to several previously. Confusion and initially a loss of trust in an individual doctor, generalized to the hospital, may manifest to a position of ontological insecurity, such that the patients world view and assumptions have been so changed by the AE that they choose different life courses. Shutz discussed the life lived within the context of assumed mutual expectations and social boundaries (Shutz, 1962, p.23). Blakie discussed social reality as understood from the inside (Blakie, 2007, p180). Giddens writes in a similar vein to Shutz, in terms of an individual’s expectation and reliance upon what to expect in one’s everyday life, the day to day assumptions that keep individuals and communities ticking over (Giddens, 1991, p.36). He points out however that the taken for granted shared reality is in fact both “sturdy” and “fragile” (ibid, p.36). The onset of illness may result in an existential crisis, the self and personal identity under threat, and an ontological threat may also manifest for patients who suffer an AE because the world as they thought they knew it, is turned upside down.

3. The different perspectives of Illness as between Doctors and Patients particularly in regard to the patients’ lived experience of illness, over time.

A number of theorists have commented from their own perspective about this perceived difference in attitude. S.K Toombs commented that in her
personal experience there was a “decisive gap” between her lived experience of a chronic illness and the capacity of a doctor to enter her world and see her situation from her point of view (Toombs, 1992, p.42). However for patients without a background of regular hospital admissions, being queried about their condition of discomfort and pain, with the implicit suggestion that it may have a psychosomatic cause may lead to a further assault on the sense of self and identity (Garro, 1992, p.104).

4. Making meaning out of illness, a life changing event.

Patients are surprised and often shocked by the condition that they find themselves in hospital. The need to process what has happened to them, and the implications, leads to a need to make sense of the experience by talking about it to family, friends, even a researcher such as myself. Senior researchers have described the way in which the narrative has found a place in the literature about the patient experience of sickness and illness. In this Chapter, I refer to the work of Garro and Mattingly (2001, p270); Good (1994); Charmaz (1999); Brody (2003). The extensive contributions of Arthur Frank and Eric Cassell to the making of meaning of illness, and insights into the patient experience are discussed in this Chapter.

There are four parts to this Chapter, the first describing patienthood and the patient experience of illness, and the second describing patient responses to the injury resulting from the AE. In the first part, I begin with literature giving an “outside looking in” perspective of the patient, as an object, linking with the Foucault “medical gaze” described in the previous Chapter, but now from a sociological “sick role” perspective. This leads to different models of patienthood; I continue with and distinguish between a doctor’s view of disease as distinct from a patient experience of illness; follow with an “inside looking out” perspective of illness, with first person accounts of illness, of being in the position of being a patient, and the reflections that drew forth: S.K Toombs, Eric Cassell and Arthur Frank speak from first hand experience. I then discuss trust as the foundation of patienthood. In the second part of this Chapter, I discuss the patient experience
of and response to an AE: an injury coming on top of an illness. Studies suggest that more than an “Open Disclosure” protocol is required following an AE (Ledema, 2011), (Mazor, 2013).

Models of Patiennenthood

In the preceding Chapter I described how models of doctoring had evolved over time from a traditional, paternalistic style to one today which requires a much greater participation by patients. Patiennenthood has evolved in tandem with this trend, and there are two discernible models. In this Chapter, I have examined what it means to be a patient both theoretically, an outside looking in approach, patient as object of observation and an inside looking out approach, patients telling stories about an experience of illness. I have done so within the framework of the existing literature. I have examined the social construction of illness and identified some similarities and differences with an AE experience.

1: Passive Model

The traditional model was of a passive patient who was permitted to enter into a formal “sick role” (Parsons, 1951) with the co-operation of others, most particularly the sanctioning by a doctor. This involved the confirmation of a genuine illness, often in a work setting evidenced by a “sick certificate” signed by the doctor, which obliged an employer to continue to pay the salary or wages of the patient even though he or she did not attend the workplace for a period of time. In a reprise of his earlier work, Parsons (1978, p.21) described illness as socially sanctioned and economically framed, a three way contract between society as a whole, doctors as gatekeepers and monitors, and patients. The patient was permitted to withdraw temporarily from their usual range of social obligations with the expectation that they would do all within their power to resume their responsibilities as soon as practicable (See also Helman, 1990, p.93). In the context of a paternalistic doctor and patient relationship, the patient adopted a “doctor knows best” view, deferring to the doctor’s opinion, and agreeing to the proffered treatment plan (Emmanuel and Emmanuel, 1999). The passive patient deemed the doctor worthy of his or her trust, on the basis of their medical knowledge and practical experience but also because it was assumed
that the doctor would act as a “genuine trustee” of the patient’s health and put his or her interests first (Parsons, 1978, p.26). The patient, of necessity, has to trust the doctor, but the ill person also wants to trust the doctor, the person in charge of managing their medical condition (Lupton, 1996, p.164).

Reir argues that there is a need for a Parsonian sick role model in the case of acutely unwell patients in hospitals who cannot act for themselves (Reir, 2000, p.68). This was something of an epiphany for him because hitherto, as a medical sociologist, he had subscribed to the view that the Parson model was passé and adopted an “activist patient stance”. However, with the sudden onset of an acute illness which required an extended stay in ICU, Reir was rendered completely dependent on the medical team. He was, he says, “too sick to know certain details of my case, too weak to be a partner in decision-making” (Reir, 2000, p.75). As a critically ill patient, Reir was content to place his full trust in the staff, there being no other option, and was grateful, in retrospect, that he had been spared the full details of the seriousness of his medical condition, a fact he described as “lifesaving” (Reir, 2000, p.81). Reir concluded that traditional paternalism was an appropriate, indeed necessary, medical response to a critically ill patient (Reir, 2000, p.88).

2: Active Model

The active model of patienthood developed in line with changes in law and medical ethics recognising patient rights to participate in decision making about their care. As I noted in the preceding Chapter, strong paternalism on the part of doctors, or the Parson model of the 1950s, was deemed no longer appropriate. Patient autonomy was defined as a key ethical principle, and informed consent mandated by law (Skene, 2004).

Burnham discusses the social changes that took place in the second half of the 20th century citing the consumer rights movement of the 1960s and the Western free market model of the 1970s and 1980s as providing the backdrop for the emergence of patient rights and patient empowerment concepts (Burnham, 2012, pp 13-14). The idea of informed consumers exercising power and influencing the behaviour of corporate entities through choice easily transferred to the health
system. Patients were re-positioned as consumers of medical services, having agency and the capacity to make informed decisions about their health care, choice of doctor, and treatment options (Burnham, 2012, p.7). Access to information resources on the Internet meant that doctors were no longer able to claim to be the sole repositories of medical knowledge (Cassell, 2004, p.18). As I noted in the previous Chapter, the health care system was also undergoing rapid change as the burgeoning costs of public health budgets resulted in a purchaser provider model of health care delivery in which government was purchaser and hospitals and doctors providers. Medical care became a matter of resource allocation and pricing, and medical decisions essentially business ones. In a cultural sense, this change was consistent with the patient as consumer of medical services, notionally making rational decisions about “purchases” in the same way they would choose any other good or service.

Burnham noted that technological advances particularly in terms of medical imaging allowing individuals perceived to be at risk or predisposed towards certain conditions to be screened before symptoms appeared, rendering the traditional sick role less viable (Burnham, 2012, p.15). Having placed the rise of the patient rights movement in an historical context, Burnham also asserted that the denouement of the Parsonian sick role model was a change in research focus by sociologists from patients, to preventative health strategies and how to encourage people to live healthy lifestyles (Burnham, 2012, p.3).

In the 1990’s there was another factor contributing towards patient alertness and activism being the reports of AEs, as documented in Chapter 2, which drew to public attention that what had been assumed to be a benign, if less than perfect, health system had flaws resulting in actual harm to patients (Vincent and Coulter, 2002, p.76). This was unsettling and led to a suspicion that the medical collegiate may preference their own rather than putting the interests of patients first (Cruess, 2002; Cassell, 2004, p.16). Patient safety became a new watchword, and with it a call to action for patients to become involved in the medical decision making process and “partner” with doctors (Vincent and Coulter, ibid) and conversely for doctors to listen to the opinions of patients. The information provided, or opinions shared, by patients with their doctor had often been
devalued by the latter, who considered them an overreach by a person without medical training (Koeck, 2014, p.7485). However, the contribution that patients could make to their care began to be recognized. It was important Vincent argued to take patient concerns about their treatment or reports of side effects seriously, rather than dismiss them as being beyond the competence and experience of the patient concerned in the paternalistic, “Doctor Knows Best”, style (Vincent, 1994, p.1613). Patients had a role to play in improving patient safety by entering into a partnership with doctors regarding their treatment and care. A patient adopting an activist stance needed to be sufficiently informed in order to choose an appropriate clinician; to help identify accurately the diagnosis; to discuss and agree treatment options; and to report any side effects or AEs promptly (Vincent and Coulter, 2002, pp. 76-77). Vincent also suggested that it was especially important to take the views of seriously ill patients into account or to involve family members in clinical decision making processes (Vincent and Coulter, 2002, p.76). Similarly, the parents of young children have a critical role to play in the delivery of safe paediatric care as the “eyes and ears” of their children, reporting any changes in the child’s condition including perceived errors in the treatment regime (Micalizzi and Bismark, 2012, p.1235). The authors argue that doctors need to draw on parents as a resource, and listen to and respect the advice offered. A recent Coronial Inquiry in Victoria heard evidence from parents whose baby son died in hospital. They testified that they kept reporting their concerns about their son’s condition which they perceived to be deteriorating but were ignored. The hospital subsequently made changes to practice to try to prevent a death in similar circumstances by introducing a rule that staff should factor in parental concerns when making decisions about calling in the medical emergency team. The parents declared that they remained angry about the way in which their son died and felt let down by a health system they thought they could trust (The Sunday Age, July 12 2015, p.19).

The active model of patienthood is appealing insofar as it represents an ideal of an informed and empowered patient and a listening and receptive doctor or hospital system. The extent to which it is realistic is a moot point and particularly in the context of an acute, very ill patient as Reir described in the previous section. The active model of patienthood assumes clarity of mind and
a sense of personal agency which may not be available to a very ill patient, a
surprised patient, an emergency patient. The active model may be more
appropriate for the chronically ill patient who over time has explored his or her
medical conditions, including the relationship(s) with doctors. The contested
notion of patienthood is part of the theoretical background for this study.

The Patient Experience of Sickness and of Illness

When men and women enter into the public hospital system, they are in a
vulnerable physical and psychological state because in some way their body has
let them down, the everyday performance of which had been taken for granted,
body as friend, one’s sense of self had been challenged. It relates to what
Giddens has labelled as “ontological security” (Giddens, 1995, p.36). At the point
of entry into hospital, an individual has a certain set of socially constructed
assumptions about being cared for, expectations about the way in which the
treatment will proceed, and the overall outcome. An admission to hospital is also
an admission, by the patient to him or her self, in a personal sense that their body
has a weakness, requiring medical treatment. Hospital admission requires trust in
the admitting doctor and the hospital system: there is no other option. Individuals
become less of themselves, the selves that lived outside the hospital
environment, in their own worlds of personal connections and responsibilities.
These roles have to be relinquished with hospital admission, as adults are
morphed into the state of being a patient, identified by plastic wristbands and UR
numbers, disrobed and dressed in standard issue hospital gowns, and disposable
boots. The reductive nature of the admission process challenges the sense of
self, as personhood becomes patienthood. Reir reflected how decisively his old
life fell away and with it his authority and personal agency (Reir, 2000, p.72). His
world contracted to an ICU cubicle, populated by doctors, nurses and visitors,
others were in charge he reasoned and “everything was under control” (Reir,
2000, p.79).

Different Perspectives of Illness as between Doctors and
Patients

For many ages, the process of succumbing to sickness was viewed as a matter
of destiny or fate, the hallmark of which was a changed relation with the world at large entailing a loss of identity (Herzlich and Pierret, 1984, p.130). In a Christian world view, illness was seen as a warning, possibly a punishment, and elicited a turning inwards to examine one’s life suffering could be the means of salvation.

The Western medical model usurped this traditional understanding of the meaning of illness, orientated as it is to action in order to conquer disease (Herzlich and Pierret, 1984, p.131). Kleinman described the different perspectives of doctor and patient in terms of different “explanatory models” (Kleinman, 1986, pp.38-39). Kleinman concluded that there was a need for concepts and models which incorporated a multiplicity of factors in understanding illness, as distinct from sickness. These are different constructions of the same episode of sickness: the patient brings an experience of illness to the doctor, but the doctor reconfigures it in terms of the biomedical model as a biological disorder requiring a diagnosis and accurate treatment of a disease. Kleinman differentiated between disease and illness being different constructs of social reality as understood in the same episode of sickness as between doctors and patients. Kleinman’s analysis of what may contribute towards “healing” of patients separated out the physiological, psychological, social and cultural aspects constituting patienthood (Kleinman, 1986, p.35).

However, the power invested in the doctor in the medical encounter may result in the patient’s explanatory model being subordinated to the medical model of disease (Helman, 1990, p.95) (Kleinman, 1986, p.129). S.K. Toombs considered that there was a “decisive gap” in understanding as between doctors and patients which had significant implications for the efficacy of medical treatment, arguing that unless the doctor has an understanding of the patient’s apprehension of illness, as a lived experience, as distinct from a disease, the doctor could not alleviate suffering (Toombs, 1992, p.42). As a person suffering from multiple sclerosis, Toombs distinguished between the typification of her symptoms and disabilities in a medical sense, and her unique experience of her illness (Toombs, 1992, p.22). The inner and subjective nature of illness she argued meant that there was an “unshareability” aspect about it (Toombs, 1992, p.23). The ontological assault occasioned by chronic illness caused sufferers to view their bodies with suspicion, the taken for granted nature of embodiment was undermined, giving rise to an acute sense of vulnerability (Good, 1994,
Reir observed that the experience of chronic illness, as documented in the medical sociology literature, appeared to be more disruptive than his own experience of an acute illness because there could be no expectation of him continuing to lead a normal or quasi normal life: his old life had been replaced. Chronic illness he postulated competed with one’s old life insofar as sufferers were expected to carry on and lead a normal life to the extent that their symptoms and disabilities would allow (Reir, 2000, p.72). Chronic illness also challenges the biomedical view that objective knowledge of the human body and disease could exist in the absence of an understanding of the subjective experience of illness (Good, 1994, p.117). The gap in understanding of the experience of illness further widened if doctors queried the patient’s account of pain or symptoms, suggesting there may be underlying psychosomatic reasons. This constituted a further assault for the patient because it apportioned blame to the patient for his or her medical condition (Garro, 1992, p.104).

Illness is something that patients grapple with, but doctors may not see or witness it because medical training requires the diagnosis and treatment of disease rather than the healing of a person with an illness: there is a difference (Cassell, 2004, Toombs, 1992, Frank, 1995 and 2000). Kleinman has argued that in the case of the chronically ill, good clinical care requires empathetic witnessing of the suffering of the patient (Kleinman, 1988, p.10). Similarly, Cassell observed that the hallmark of a good doctor was his or her capacity to convey to the patient that their suffering could be relieved, and a sense of wholeness restored, allowing for a new iteration of their life story in the light of their illness, through empathetic listening and relationship (Cassell, 2004, p.287).

The way in which illness is understood and the meaning that it has for a patient transcends the processes and vulnerability associated with hospital admission. A patient presents to hospital as a person with a past, a range of experiences that have informed the way they view the present, a cultural background, and a set of expectations about the future, which set them up for hospital admission and what happens next. As Macintyre observed, individuals approach their circumstances as “bearers of a particular social identity”, being the imputed characteristics of family, culture, social connections and social expectations (Macintyre, 1987, p.220). Each patient has an individual story that they bring to their hospital...
admission, and not simply about medications taken or past hospital admissions and procedures, but about themselves. A patient’s life experience forms the backdrop to the experience of sickness and illness (Cassell, 2004, p.37). It is an individual experience, the interpretation of which has been framed beforehand, within the context of an individual’s life, through a personally formed and framed life lens. The way in which patients view the present, lying in a hospital bed, or reflecting on the experience of sickness, illness, afterwards, comes from their life experiences. Turner, Fabrega and Radley discussed the way in which sickness, illness and healing are socially and culturally constructed (Turner, 1995, p.207; Fabrega, 1972, p.8; Radley, 1994, p.2).

The “stock of knowledge” available to people to interpret their lives in an ordinary and everyday sense is socially derived (Shutz, 1970) and works on the basis that others that we connect with in an everyday sense have a similar, shared, understanding of the world as we see it: this is the basis of friendship, but not necessarily a doctor and patient relationship. One’s life at any moment in time is in a state of flux according to individual circumstances. The desire for a sense of the self, as a same self, as part of the continuity of one’s life over time, is challenged as life events intervene (Shutz, 1970). There is a need to construct and reconstruct oneself in order to meet the exigencies of life and this is done in the form of narrative which provides the medium for making sense of one’s life (Bruner, 2002, p.64).

The need to tell stories about one’s life experience in order to make sense of it is not confined to the context of illness, but the experience of illness often provides an opportunity for reflection, offering a before and after perspective. A connection between stories told, personal identity and temporality was identified by Ricoeur (Ricoeur, 1984 and 1992) drawing on St Augustine’s explanation of time as a before, present and future concept (Augustine, 1961). In “Time and Narrative” Ricoeur reflected that it is a feature of every human age and culture to try and chronicle time as a way of interpreting and understanding experience (Ricoeur, 1988, p.106).

Within a concept of time one can locate oneself and one’s personal life story:
identity, Ricoeur argued, must be understood in the sense of oneself as the self-same over the course of one’s lifetime (Ricoeur, 1998, p. 246). He developed this idea further in “Oneself as Another” in that an individual brings to his or her everyday life a way of understanding the world, a “prefiguration”. There then occurs an event that is unexpected, surprising, and in what Ricoeur terms “the paradox of emplotment” the contingent event is configured into the personal story as integral to it when it is understood and reflected upon retrospectively (Ricoeur, 1992, p. 142). Narrative identity is an iterative process. Hurwitz argued that the temporal element was critical to the construction of an illness narrative providing a framework linking a person’s knowledge of who they were prior to the onset of illness with who they were becoming and where they may be going: the evolving patient/person (Hurwitz, 2004, p. 423). The passage of time provided the requisite distance for the patient from the biological reality, allowing mental, emotional and interpretative processes to take place (Hurwitz, p. 424).

**Illness Narratives: Making Meaning out of Illness**

Illness narratives are a subgenre of narrative and storytelling, the purpose of which is to tell the story of a life disrupted by illness (Garro and Mattingly, 2001 p. 27). Good observed that much of what is known about illness is known through stories, whether told by the patient, family members, or doctors (Good, 1994, p. 164). The story makes accessible the experience of illness to the patient, both as narrator and as “reader”, and to others (Good, 1994). Stories of suffering provide an opportunity for reflection and adjustment to one’s altered state (Charmaz, 1999, p. 374). Brody argues that a joint construction of the “healing” narrative is the preferred form, which is to say that the doctor facilitates the work undertaken by the patient in re-fashioning his or her story in the light of the experience of illness (Brody, 2003, p. 16). He further argues that the sick have an obligation to tell stories about their experience in order to bear witness to the strength and resilience of the human spirit to the community at large (Brody, 2003, p. 139). There is learning for others from listening attentively to illness stories, reminding us as they do of our common humanity and need to respond to life disruptions and setbacks (Brody, 2003, p. 140). He concludes that illness narratives give rise to epiphanies, new knowledge and insights (Brody, 2003,
The refreshing aspect of Arthur Frank’s “The Wounded Storyteller” analysis of patient experience is that it places the patient centre stage, as the subject and central character in their own experience of illness and hospital stay. The story is told through a wounded body. The loss of the “destination and map” that had hitherto guided the person’s life and world view, as described by Frank (Frank, 1995), is highly relevant to patients who have suffered not just an illness, but also an AE. Frank identified three potential ways of experiencing and responding to illness and telling one’s story as an ill person. The first is in the restitution framework. Frank argues that this is the culturally preferred method in Western society as it represents the defence mechanism to fear of one’s mortality. It looks to the future in which one is restored to one’s former state of health or well-being. It retains a belief in the curative possibilities of medical interventions. Frank describes the people who adopt this stance, usually the recently diagnosed, as telling the story from the sidelines in the sense that “others” are playing the lead role in bringing about the anticipated restitution (Frank, 1995) and things will come right. In this context, finding the “right” doctor in whom to trust, after being disillusioned with the first doctor consulted, represents an important milestone in the plot of the narrative (Brody, 2003, p.85). Frank argues that the ability to tell one’s story, to recount the experience of illness, to share that with others and then to reflect and possibly recreate a personal account is therapeutic and potentially empowering. The telling of the story is, according to Frank, part and parcel of learning to “think differently” about oneself in one’s new state as an ill person (Frank, 1995). He concludes that the restitution narrative is ultimately false because life is never exactly the same after an illness, and particularly in the case of a chronic illness. Telling one’s story, is an active, constructive and creative process (Garro and Mattingly, 2001, p.7).

The second choice that Frank identified for patients is a story of chaos. In this case, there is said to be for the patient a descent into crisis as more complications arise, potentially more mistakes are made, and there is a loss of belief in the possibility of return to one’s previous self. In other words, it is diametrically opposed to the restitution view of the world. Frank notes that there are not “stories” per se in the chaos commentary, and indeed if a story were to
be told with a structure including a beginning, a middle and an end, it would mean that the individual may have entered into a potentially new and therapeutic zone (Frank, 1998). The final form that Frank identified is the quest story.

“Quest” as defined in the Concise Oxford Dictionary is a “seeking or thing sought by inquiry or search”. Frank defines his quest group as people seeking to find meaning from their experience of illness and suffering and turn it into something positive. It can be referred to as “learning”, as a result of which they have made changes in their lives directly or adjusted their perspectives and world view through new insights. Frank is essentially speaking of people learning to live with chronic and or debilitating illness. He cites S. K Toombs’ (Toombs, 1992) journey with multiple sclerosis, and the way in which she sought to recreate herself, through and because of her illness (Frank, 1998). The Frank definition of quest refers to a personal journey of introspection and development. The perspective offered is that of an assault constituted by illness, of the changes that it brings forth in one’s life and the lived and reflected upon experience. The need for recognition of suffering and of the patient experience is emphasized. Cassell considers the nature of suffering in the context of the doctor and patient relationship noting that medicine is a moral enterprise and concluding that recognition of suffering by the doctor can facilitate a patient’s pathway to healing, broadly defined (Cassell, 2004).

Cassell and Frank have made important contributions to the patient literature by writing reflective accounts of their own experiences as doctors on becoming a patient including the way it challenged or changed their lives and sense of identity (Cassell, 1978, 1991, 2004). (Frank 1995, 2000). In addition, Frank offers a framework for understanding the patient responses to illness which is also useful in the context of the pathways undertaken by patients who have suffered AE

**Trust as the foundation of patienthood**

A patient has a basic need to trust in the doctor(s) in the context of their illness, respectful of both medical knowledge and practice (Cassell 2004, p.72). A patient entering into the public hospital has hopes and expectations of both the doctor and the institution, that they will be looked after (Hayes, 2010). Patients entering
into the public hospital system, typically have no choice of doctor, though there may be exceptions where a prior consultation has taken place. In any event, trust is “dynamic and fragile” at the point in time when a patient enters hospital care, and expects to be taken care of (Mechanic, 1996, p.173). The doctor and patient relationship can in some instances mirror earlier experiences of anxiety, from a younger age, reaching back to childhood. Trust is backward and forward-looking. Trust has as its genesis in the early days, childhood roots, and over the course of a life may take a tumble from time to time, but trust is part of human psychology, and forward looking, particularly at the time of entry into hospital. This is a point at which one has to surrender oneself to others, trusting that all will come good, one will become well. It is not a moment in time in which a typical patient feels sufficiently empowered to request a doctor to disclose all potential conflicts of interest associated with his or her case (Bending, 2015). Rather, as Bending concludes after a legal analysis, that trust lies at the heart of the doctor patient relationship and requires a full and frank exchange between both participants so that decisions are made mutually respectfully and in good faith (Bending, 2015, p191).

At the moment in time a patient enters hospital, he or she is reduced, dependent, and just hoping that all will go well. The sick person is often not up to the task of making clinical decisions or contributions to their care (Toombs, 1992, p.12). It is difficult to be clear-headed and view clinical choices dispassionately when one’s taken for granted life has been rendered less certain by the onset of illness (Toombs, 1992, p.20). Doctors who become patients, whilst possessing medical knowledge and therefore having the capacity to contribute to their care decisions, have been surprised by the different perspective that being a patient confers, when the concern is about the lived experience of illness rather than the treatment of disease per se (Toombs, 1992, p.12). The patient experiences a loss of control, and is dependant and reliant. The need to trust is absolute. The icon used on p.141 reflects the expectations of the patient and the doctor in a tender and idealistic way. In the preceding Chapter, I documented the commercial dictates of the modern Western hospital environment. Doctors have less discretion, and are required to work within administratively approved diagnostic categories and treatment options, which can exacerbate the tendency to regard
patients as standardized objects, rather than individuals with a unique, to them, illness (Freidson, 1988, p.388). This runs counter to the trust that patients place in doctors to hold them in their mind and put their individual interests first.

**Patient Responses to an AE**

Patients enter hospital in a vulnerable physical and emotional state, trusting in the care to be provided. An AE is therefore a particularly confronting experience, distinguished from other types of accidents, because the patient is harmed, albeit unintentionally, by the very people he or she had trusted to look after them (Vincent, 2003, p.1054). Further, the patient may be treated by the same doctor who caused the injury, or at least members of the same profession will be involved in the patient’s ongoing treatment and care. Initial reactions to an AE are likely to be severe: a mix of emotions involving loss of trust, fear and anxiety about future treatment, and a sense of isolation (Vincent, 2003). The impact of the AE for the patient is further exacerbated if the incident is handled poorly at the time (Vincent and Saunders, 2005, p.6). In two studies, Vincent and colleagues investigated why patients sue after an AE. Patients who had suffered an injury during a surgical procedure reported long term, detrimental effects on work, family relationships and social life (Vincent et al, 1994, p.1609). There were 4 main factors that influenced their decision to take legal action. First, there was a concern about standards of care and a desire to ensure that a similar incident did not occur in the future. Secondly, patients wanted a full explanation as to how and why the AE occurred. Thirdly, there was a desire for compensation for financial losses, pain and suffering or to provide for future care needs. Finally, patients wanted the doctor and/or the hospital to be held accountable for the error (Vincent et al, 1994, p.1612). In identifying these factors, Vincent noted that they extended beyond what the legal system and process was designed to deliver for a plaintiff, which is compensation (Vincent et al, 1994). Obtaining a full explanation was essential and failure to do so could be experienced as distressing and provide a stimulus to take legal action (Vincent, 2003, p.1054). In an earlier study of the patient perspective following obstetric accidents, a number of parents reported that they embarked on a legal process in order to receive a proper explanation as to how and why their child had come to be harmed (Vincent et al,
Vincent opined that in taking legal action patients may also be attempting to get the doctor or the hospital to pay attention to their plight, and to force them to make changes to their practice or system so that a similar AE did not happen to another person (ABC Radio National, *The Health Report*, Broadcast 15 July 2002).

OD protocols were introduced as a way of responding to the patient’s desire for an explanation as to what, how and why an AE occurred. In a study investigating patients’ and family members experience of OD, and to identify ways of improving delivery, Iedema and colleagues undertook a retrospective qualitative study involving semi structured in-depth interviews with 100 former patients and family members (Iedema, 2011). The study found that notwithstanding the promotion of OD, the practice failed to meet patient expectations. Issues cited included the need for better preparation for OD, a two way dialogue rather than a one way flow of information, follow-up support, and evidence of patient safety improvements. Interestingly, a number of participants in the study had been forced to demand OD, souring the process from the start. Others lodged formal complaints or initiated legal proceedings in order to obtain it. Where OD was offered, it was often found to be inadequate, experienced as lacking genuine dialogue, ready acknowledgement of the AE by the doctor, and a sincere apology. The proffering of formal investigative findings using systems discourse language of “root cause analysis” of the cause of the AE failed to impress patients (Iedema, 2011).

The effectiveness of apology and disclosure practice has also been considered in a study of cancer patients in the United States (Mazor, 2013). The process of disclosure fell short of patient expectations, and whilst there was an appreciation of an apology, there was a perceived disconnect between the words offered and action taken in terms of change in practice and doctor learning from the AE. The study concluded that patients wanted more than words, rather recognition of the suffering caused to patients by an AE in a general sense, including the impact that it had had on their lives, and that lessons had been learned from their personal experience and put into practice by doctors in order to prevent recurrences (Mazor, 2013).

In a further iteration of the patient response to an AE, an escalation of response
due to lack of information, provided the impetus for the creation of the patient advocacy group Medical Error Action Group (MEAG) formed in Australia in order to hear the concerns of patients and family members who had suffered an AE and wanted to take advice and seek support following an AE. MEAG was founded by Mrs Lorraine Long, who lost her mother to an AE, and whose death was the subject of a Coronial Inquiry in Victoria. The findings of the Inquiry revealed that serious medical errors had contributed towards her mother’s death.

**Conclusion**

In this Chapter I introduced the reader to the four key theoretical underpinnings of my thesis that will inform my findings and conclusions. I have examined what it means to be a patient both theoretically, an outside looking in approach, patient as object of observation and an inside looking out approach, patients telling stories about their experience of illness. I have examined the social construction of illness and identified some similarities and differences with an AE experience. I have differentiated between passive and active models of patienthood, and argued that the active model of patienthood is an aspirational goal, but not a realistic one for many sick patients. I have considered the need to both tell one’s story and/ or reframe it at significant moments in time in order to make sense of life events. In the next Chapter, I document the methodology I adopted to explicate the patient experience of an AE, and in the subsequent findings Chapters, the reader will get to know my participants through their first hand accounts of a medical error, the way in which it changed their lives, and transformed their taken for granted assumptions about the world as they knew it, including trust in doctors, and public hospitals as trustworthy public institutions.
Chapter 5:
Methodology

In this Chapter, I document my methodological approach. I undertook a qualitative study, informed by a number of academic disciplines. The underpinning ontological and epistemological assumptions of my research are based in the interpretive tradition of social research. I draw on narrative theory as a theoretical framework. I describe my research plan and recruitment process of 3 groups of participants, 33 in total, who took different pathways to resolve their AEs. I undertook a 2 stage in depth interview process over 3.5 years and subjected my data to qualitative analysis using techniques of thematic analysis. I mapped the themes in diagrammatic form and abstracted the 4 key themes into a model explicating the dynamic relationship between them.

I used pseudonyms for all research participants. Where quotes are used, some of which were truncated, participants are identified in the following way:-

Pseudonym;age;Hospital/HSC/VMIA;1st/2nd interview.

5.1: Aims of the research
The aim of my research project was to explore the experience of patients who had suffered an AE during their hospital stay, at the time, and over time.

The research objectives were to:-

a) explore the effect it had on their lives;

b) explore the meanings they ascribed to it;

c) investigate the actions taken (formal or informal) in response; and

d) explore the factors and/or interventions that may assist in meeting patient needs following an AE.

5.2: An interpretivist approach
The ontological and epistemological assumptions underpinning this research are
based in the interpretivist tradition of social research, emphasising the socially constructed nature of reality and the contribution of human subjectivity to knowledge without compromising the objectivity of knowledge (Schwandt, in Denzin & Lincoln, 2000, p.193). Building on the work of Weber (1864-1920), Schutz (Schutz,1962) argued that social actors interpret the world through the use of common sense constructs. The social scientist then draws on these common-sense constructs to build their understanding of the phenomenon of interest.

Schutz discussed the socialisation of knowledge in terms of the assumption between social actors of the reciprocity of perspectives; the “handed down” nature of knowledge according to one’s biographically determined situation, typically transmitted through the vocabulary and syntax of everyday language; and the fact that the stock of actual knowledge differs as between individuals, in terms of what is known and also how they know the same set of facts. In Schutz’s view, social life takes place within the context of the typifications used by social actors to describe both persons and the courses of action undertaken by them ( Schutz, 1962, p.23). In order to “understand” an action of one by the other, an actor needs to construct an underlying motive to the observed act. From this point Schutz concluded that the meaning of an action is necessarily different for the actor, the participant in the action and for a third party observer (Schutz, 1962, p.24). Social reality is discovered from the “inside”, that is from the perspective of the participants (Blaikie, 2007, p.180).

From the outset, my aim was to discover the meaning that the AE had for people both at the time and over time. People would have their own unique response to an AE, informed by their social location, perspectives and past experiences. I saw my role as interviewer as being to elicit as far as possible their individual views of their worlds (Rubin & Rubin, 2005, p.27). In attempting to do so, I was also aware of the cultural values and assumptions that I brought to each interview that in turn may have shaped the interaction that took place and the interpretations that I subsequently made (Holstein & Gubrium,1995, p.3). Qualitative inquiry is seen as “value bound” in this regard (Higgs in Byrne-Armstrong & Higgs, 2001, p.46).Indeed as Rubin and Rubin noted, responsive interviewing relies on an interpretative constructionist philosophy, in that there is
recognition that both the interviewee and the interviewer are human beings who form a relationship during the interview that generates ethical obligations for the interviewer (Rubin & Rubin, 2005, p.30).

5.3 Research Strategy

Given my ontological and epistemological positions, I chose in-depth interviewing as my data collection method so that I could hear first hand participants’ experience of an AE and the meanings they ascribed to it (Minichiello et.al, 1990) p.100. I then used an analytic induction method in order to allow ideas to emerge from the data and so begin the process of theory building (Minichiello et.al, 1990) p. 286. I was attracted by the constructivist approach put forward by Charmaz, (Charmaz, 2000, p.509). A constructivist approach requires an interactive process between the viewer, or interviewer, and the interview participant. It is not one-sided and what the researcher brings to the interview will shape the outcome of the interview (Charmaz, 2000, p. 524). In approaching my interviews with participants, I did not assume that there was a single, universal truth regarding the experience of an AE (Charmaz, 2000, p.523). Rather, I sought to listen to their stories of their AE experience with the aim of understanding the meaning that it had for them. The themes that emerged during the first round of interviews shaped the style and content of the second round interviews. By doing so I was able to construct a theory around the AE experience inductively arising from the views, attitudes and perceptions of my participants.

5.4. The Research Path and Plan

1: Preliminary stage: the study context

As previously noted, my interest in the patient experience of an AE began when I was a pastoral care worker in a major public hospital. I explored with several public hospitals whether there was any interest in investigating AEs in a hospital setting but management declined citing concerns about potential legal liability issues. My next step was to contact the Victorian Managed Insurance Authority (VMIA), the Victorian public hospital insurer. I met with Senior Officer Dr Jack
Bergman who in turn introduced me to Dr Michael Buist (MB) a senior clinician at a public hospital. We all shared an interest in the findings of the Veteran’s Affairs Hospital in Lexington Virginia, USA, where a disclosure of medical error had been reported as assuaging patient anger and reducing incidents of litigation (Kraman, 1999), so there was a coalescence of interest as between the hospital indemnity insurer, a medical doctor, and me coming from my observations of different patient responses following AEs.

My formal research began as a study of AEs with the backing of VMIA and the collaboration of MB. VMIA agreed to support an exploratory study about an OD process at the hospital where MB worked. Critically, VMIA indemnified the hospital site against any legal/patient claims that arose following an OD. It was only with that assurance that the Hospital Research and Ethics Committee approved a limited study that was the precursor to OD studies in Australia. The definition of an AE, for the purposes of the study, was set by VMIA and was an unplanned operation, unplanned intensive care unit (ICU) admission or an unexpected re-admission to hospital. Whilst the definition was in line with the Quality in Australian Health Care Study (1995), being an injury caused to the patient as a result of the health care received during hospital stay rather than their underlying medical condition, VMIA set the selection criteria for study participants so that AE’s associated with Accident and Emergency, Obstetrics, Paediatrics and Neurosciences were specifically excluded, as were any cases referred to the Coroner. The study was therefore limited to the general medical and surgical wards. There were two reasons given for the exclusions. First, it was deemed too difficult to identify and document error in the often fast-moving Accident and Emergency Department. Secondly, VMIA was concerned that an OD of error in the other often highly emotionally charged clinical areas could invite legal action against the hospital and clinicians. By mandating that the study focus on what it considered as “lower risk” AE’s, VMIA was attempting to allay the concerns of the site hospital management. However, VMIA was still required to indemnify specifically the site hospital and the clinicians involved in the study as a prerequisite for receiving approval to proceed from the Human Research Ethics Committee. The VMIA perception as to what constituted “lower level” AE harm will be discussed in the context of the patient experience in Chapters 6, 7,8 ,and
VMIA introduced a further “safeguard” into the study design by reserving to itself a right of veto over the deliberations of the Steering Committee set up to consider the suitability for study inclusion of hospital patients who met the study selection criteria. The power could be exercised for any reason whatsoever, but was in fact only used once. The way in which the Steering Committee worked is described in the next Section.

In the original application to the Human Research Ethics Committee in February 2002, the study was to have been limited to 20 participants recruited as Hospital patients. In an operational sense, an AE was to have been identified by an unplanned operation or re-operation; an unplanned admission to ICU; or an unplanned hospital re-admission. Length of hospital stay greater than would have been anticipated by the initial admission diagnosis was also to be screened as a potential indicator that an AE had occurred.

In a substantive amendment to the original Ethics application I sought and obtained from the Research and Ethics Committee approval in July 2002 to recruit up to 80 patients and former patients of the public health system who had suffered an AE during hospital stay. The principal reason for the amendment was my desire to purposefully obtain data from two additional groups who had suffered an AE. Purposive sampling is used in qualitative research in order to access information-rich cases that fit the study (Patton, 2002, p.46). Data obtained from individuals who had either lodged a formal complaint with the Office of the Health Services Commissioner (HSC participants) or had sued and settled following an AE (VMIA participants) would add greater depth to my data. Further, by nature of the time taken by the complaint and legal processes respectively, potential study participants were at a distance of between two to six plus years from the AE, when they spoke with me. I was curious as to whether this made a difference to their recounting and perception of an AE, particularly as compared with the Hospital participants for whom the experience was very current when I interviewed them for the first time, a short time after a defined AE and whilst they were still in hospital.
2: Sampling and Recruitment

The initial aim was to recruit up to 40 Hospital patients who were to be randomised by a process of sequential random number generation into a disclosure intervention group and a control group. The latter were to receive nothing less than the standard hospital practice and procedure for the management of a patient who had suffered an AE. A second group of up to 20 former patients was to be identified from the complaints register of the HSC for the two years preceding the start of the study on 1 July 2002. Prospective participants were to be matched as closely as possible with the selection criteria. I had gathered support from and access to the HSC data through a series of meetings with the Health Services Commissioner, Ms Beth Wilson, and members of her staff and enjoyed her enthusiastic support for the study. A third group of up to 20 former patients was to be identified from the “closed” files of VMIA, being cases where patients had sued the hospital and/or clinician and a legal and financial settlement had been reached.

Stage 1 - Hospital recruitment 1 July 2002- 16 February 2003

A research nurse (RN) was recruited on a .5 EFT basis with funds made available by VMIA. Her job was to screen on a daily basis, Monday to Friday, the operating theatre log for the previous 23 hours; ICU admissions; and incident reports that were filed with hospital administration. The RN summarised the AE’s that fell within the selection criteria and forwarded a report to a Steering Committee comprising a lawyer with medico-legal experience nominated by VMIA, a representative from VMIA, a representative from the senior management (medical) team of the site hospital, MB and myself. The Steering Committee was required to consider the case(s) put forward and within 24 hours indicate whether it was suitable for inclusion in the study. If the case was agreed, the RN proceeded to seek the informed consent of the patient concerned. By consenting, patients agreed to an interview whilst in hospital and also a follow-up interview 6 months later.

Randomisation into a disclosure intervention group and a control group then took place. However, during this phase only 8 patients were identified for
inclusion in the study, reflecting perhaps the constraints imposed by the selection criteria. All were randomised “in” which meant that they were scheduled to receive a disclosure intervention. In one instance, the patient withdrew consent following a discussion with a family member and in another the patient was discharged before the intervention took place.

For the 6 remaining participants, the disclosure intervention was undertaken by an intensive care specialist, principally by MB, who was not the treating doctor of the patient concerned. The process involved a detailed review of the patient’s medical record and a discussion about the AE with the treating doctor. MB reported to the Steering Committee that on occasions these discussions proved to be very difficult with some clinicians being resentful and suspicious about the trial OD process. The next step involved arranging a time with the patient for a formal OD, in some instances with relatives present, to discuss the AE. The aim of the OD was to inform the patient, and maybe family members if present, about the AE, an explanation as to what had happened, using plain language, the reasons for it, and the expected course of future health care management. In all instances an apology was given and statements made that AE’s were quite common in hospital settings. Liability was not admitted. There was an opportunity for the patient to discuss their grievances and follow-up was offered by the Doctor undertaking the disclosure if required, or with a member from the Social Work Department. It had been intended that within 72 hours of the OD the patient would participate in a semi-structured interview as to how they responded to it. However, one patient died and another was transferred to a different hospital before the interview took place which meant that 4 interviews were conducted.

**Stage 2- Hospital recruitment 16 February 2003-31 July 2003**

At this point in the study, I had regard to the very low recruitment rate, averaging 1 participant per month and the fact that using randomisation all participants had been allocated to the intervention group. Randomisation, as a process, is commonly used in clinical trials (Beller, 2002) in order to ensure that as between treatment groups, each group is, on average, as alike as possible apart from the intervention being studied. However, in a small study it can mean that the
allocation is not well balanced which is what I had found. I introduced a method of block randomisation (Beller, 2002) in order to ensure that a control group was recruited. I was also concerned that with the passage of time, and as knowledge of the study spread, the site hospital culture could become more sensitized to patients who had suffered an AE, potentially blurring a possible distinction with the disclosure intervention group.

Blocks of 4 were used and sealed envelopes were opened sequentially by the RN. In each block, 2 patients were allocated to a control group and 2 to an intervention group. Overall, 8 patients were allocated to each group. Interviews were conducted with 5 of the 8 participants in the control group: one patient was too ill to be interviewed and died soon after; another withdrew consent following a discussion with his partner; and another was discharged before the interview took place. Interviews were conducted with 6 of the 8 participants in the intervention group: one patient died and another was discharged before the interview took place. In summary, 15 interviews were conducted with Hospital participants, 10 of whom had received an OD.

**Stage 3- Recruitment of participants from HSC register, 2003**

In the 2 years preceding the start of the study, 2349 complaints had been received from Hospital patients or former patients by the HSC. Screening these cases through the prism of the study selection criteria, 30 prospective participants were identified by HSC staff. In the first instance, they were contacted in writing by the HSC, advised of the study, and offered an opportunity, without being obliged, to participate in an in-depth interview about their experience as a patient. Enclosed with the letter was a copy of the Patient Information Sheet; my contact details; a slip of paper to be filled out by the recipient indicating whether they would or would not like to participate in the study and if yes, a space where they could indicate their preferred time for me to make contact and arrange an interview, together with a reply paid envelope. I was subsequently contacted by 12 people and interviews were arranged.

**Stage 4- Recruitment of participants from VMIA/Slater and Gordon, 2004/05**

Accessing the VMIA data proved more problematic as it was not stored on computer data bases and required a physical search of files stored off-site. In
order to limit the hours required, VMIA narrowed the search to cases where Slater and Gordon, a prominent law firm with a strong litigation practice, had acted for the plaintiff and where the matter had settled in the three years preceding the start of the study. Forty-three prospective study participants were identified.

Concerns about issues of solicitor/client confidentiality were discussed at a meeting between VMIA, Slater and Gordon, the Health Services Commissioner and me. It was agreed that prospective participants would be contacted in the first instance in writing by Slater and Gordon. Letters were dispatched to 43 recipients in 2004, with the Patient Information Sheet, and my contact details, exactly as had been done with the HSC participant group. I was contacted by 6 people and interviews were arranged. VMIA declined my request to try and identify further cases.

5.5: Data Collection

I used semi-structured, in-depth interviews as my data collection method. I chose in depth interviews as my preferred data collection method because it allowed me to gain access in a personal way into an individual’s world view and interpretations (Minichiello, 1990, p.100). A focus group, by way of contrast, may have been appropriate if I had been seeking simply to gauge reactions to an AE rather than to explore the experience from an individual perspective. It would have been very inappropriate for my research aims being patient and individually focussed, though may be appropriate for other research objectives (Patton, 2015). I incorporated a two-stage interview/data collection process so that I could explore whether the Hospital participants had a different view of their experience of an AE at a point in time removed from the actual event. Additionally, the two-stage approach offered the opportunity for participants to reflect on my interim analysis of emerging themes, and for them to consider and confirm or otherwise the validity of my interpretations. I outlined my initial findings of my research in my follow-up, invitation letters, to participants. I used pseudonyms for all participants in my data recording and analysis.

Charmaz has noted in her studies of chronic illness where the interview has an
emotional content around suffering there is an expectation that the listener will be empathic and seen as someone the participant can confide in (Charmaz, 2000, p.525). For this reason, “one-shot” interviewing may lend itself to a sanitized version of events, cleaned up for public discourse (Charmaz, 2000.). On the other hand, where there has been a connection with participants over a period of time, there may be a greater opportunity for more private thoughts and feelings to emerge, and be expressed (Charmaz, 2000).

1: First round interviews
I interviewed all participants as a sole interviewer and my opening question to each one was to invite them to describe their experience of being a patient. A clarification was required for several of the Hospital participants in that the question related to the current hospital admission only. For the HSC and VMIA participants, I explained that the question related to the hospital admission that gave rise to their complaint. The only structured aspect to the interviews was that I asked the Hospital participants who had received an OD whether they had found it helpful. Similarly, I asked the HSC and VMIA participants to hypothesize as to whether they would have found an OD intervention helpful. The length of the interview varied according to participant interest but generally speaking, Hospital interviews were short, averaging 15 to 20 minutes. HSC and VMIA interviews took longer and lasted on average one hour or more.

The interview environments were very different. The Hospital interviews took place at the participant’s bedside, often in a shared hospital ward, and sometimes interrupted by nursing staff. On two occasions, family members were present. In the first instance, the participant was very articulate on her own behalf and her son and daughter-in-law merely filled in the details as to how sick she was when in ICU for nearly 10 days, of which she had no memory. In the other interview the participant’s wife spoke on his behalf. He could manage only a few words and in any event had no recollection of his time in ICU. His wife however, having practiced as a Division 1 nurse until her retirement, had very strong views about her husband’s AE. I included her comments in the transcript.

One Hospital interview was conducted through an interpreter. Having satisfied myself that the potential participant had had an interpreter to assist him in the
informed consent process, I relied upon and incorporated the interpreter’s translation of the participants’ responses into the transcript.

Notwithstanding a difficult interview environment in terms of lack of privacy, in-hospital participants agreed to have the interview recorded. I explained that the recorder could be switched off at any time, but no such request was made. When background noise became an issue, I made notes to help me decipher the recording. The interviews were transcribed verbatim and supplemented by my notes as required. I used a digital recorder in my second round interviews.

Six of the HSC interviews were conducted at participants’ homes; 2 were conducted in relatively private spaces at public hospitals (one was in a private office and the other in the Chapel); 1 interview was conducted in a meeting room at the participants’ place of employment; and 3 were conducted by telephone. In one instance, the wife of the participant spoke on his behalf. The nature of his AE had affected his vocal chords and he could only speak in a whisper. Further, as with 2 of the Hospital participants, he had no recollection of his 3 weeks in ICU and his wife was the family memory bank. With the exception of the 3 telephone interviews, the interviews were recorded with permission and transcribed verbatim. In the case of the telephone interviews, I made handwritten notes sometimes paraphrasing the points made. Where there was a particularly interesting quote, I asked the participant to repeat it and then pause so that I could be sure of writing it down accurately. I typed up these interviews and included them with the other transcriptions for analysis purposes.

By way of contrast, all of the VMIA sourced interviews were conducted at participant’s homes and the majority lasted for 90 minutes or more. All of the interviews were recorded with permission and transcribed verbatim. On 2 occasions a spouse was present and contributed to the interview. I included that data in the subsequent transcription. Another participant felt that her adult children had been involved in her AE yet their role in her care had not been recognised up until then. The participant suggested and arranged a follow-up interview with her 3 adult children shortly after my first interview with her. It took place at the home of one of her sons and her other son and daughter travelled some distance in order to be present. I included their contributions in my data.
Their mother had no recollection of her extended time in ICU and the children held that memory for her about her AE experience. At the end of the first round of data collection, 34 interviews had been conducted (including the aforementioned adult children of one participant) and transcribed. I included the observations of the adult children in the text of my findings Chapters, but it is their mother and her AE experience that features, not about her actual AE experience, but rather her experience of taking legal action following an AE. They do not feature in the diagrammes.

2: Second round interviews
Following a preliminary thematic analysis of the first round interview transcripts, described in the next Section, I contacted participants for a follow-up interview, albeit after a considerable delay in the case of the Hospital group. My first interview with them had taken place in 2002/3, at which time participants had consented to a follow-up interview some 6 months hence. It was in fact 3 years later when I wrote to them requesting a further interview. In the intervening period however I had made telephone contact with, or left messages for most participants on 2 separate occasions. The first contact was made approximately 6 months after their discharge from hospital which was the timeframe that they expected to hear from me. I made a second contact one year later. On both occasions, I explained the delay in terms of me taking leave of absence from my research, and then re-locating to another Centre within the School of Population Health at the University of Melbourne. I assured participants that the research was on-going.

Of the original 15 Hospital participants, I ascertained from the RN who was still working at the site hospital that 2 had died in the intervening period. I sent letters to all of the others and received positive responses from 6, with one letter returned to me with an “addressee unknown” stamp. I telephoned the 3 outstanding participants. One did not return my call following a message left on his answering machine and the other two declined a further interview saying that it was too upsetting to talk about their situations.

The interviews with the remaining 6 participants were conducted at their homes at a time of their choosing and typically lasted one hour or more. They were
recorded with permission and transcribed verbatim. The spouse of one participant contributed to the interview as she had in the first round and I included her data in the analysis.

I wrote to 10 of the original 12 HSC participants requesting a further interview. I excluded 2 participants from the sample with the agreement of my Supervisor (LG). The reason in one case was that I felt the participant may have mental health problems potentially unrelated to the AE. Not being an expert in such matters, but nevertheless being mindful of my responsibilities as a researcher, I did not want to risk causing her distress in any way. In the other case, I had felt ill at ease in the company of a very angry participant. It appeared to me that he exhibited a fairly generalized anger and I did not wish to be in his presence again as an interviewer.

I received 6 positive replies, including in 2 instances the day after the letter was dispatched. The interviews were conducted at the homes of participants as to 3, at a time of their choosing. Another was conducted at the office of the participant, as it had been in the first round interview. The final 2 interviews were conducted by telephone, again as they had been in the first round. However, this time I was able to record the interviews. Five interviews were recorded with permission and transcribed verbatim. Permission to record was denied in one instance because the participant had commenced legal action and his lawyers had recommended that approach. His wife participated in the interview as she had done in the first round and I included her data in the analysis. In that case, I took notes of the interview which I later typed up and included in the data.

In September 2006, I wrote to the VMIA participants. One participant telephoned the next day to accept. After two weeks, I telephoned the other participants and 3 were willing to participate. One participant did not return my call, nor respond to a second letter. He and his wife had been distressed in the first interview in recounting his AE and its consequences. I did not attempt to contact them again for an interview, although I did send them a Christmas card that year, as I did other participants, with a notation that I had appreciated his/their help, and that I was available to talk if they wanted. Another participant’s husband had died 3 weeks prior to receiving my letter and she did not feel able to continue, noting
that in other circumstances “I would have jumped at it” (Telephone conversation with Doris, 8 November 2006).

I interviewed the 4 VMIA continuing participants in their own homes and at a time of their choosing. The interviews, typically lasted between 60 and 90 minutes, and were recorded with their permission and transcribed verbatim afterwards. My second round of data collection was completed in December 2006 by which point a further 17 follow up interviews had taken place.

3: Reflections on data collection

Overall, I was warmly received by the participants who wanted to talk and reflect upon their AE experience. I was aware that the Hospital interviews were more constrained than the other participants because of the frequency of interruptions and the fact that a number of participants were very ill: I did not want to risk tiring them with a protracted encounter in our first interview. I resolved to address this in the second round interviews by ensuring that the setting, pace and duration of the interview was determined by the participants themselves.

I became aware during the second round of interviews that a number of participants had made a considerable emotional investment in my research and its outcomes. There was mild criticism expressed by several that I had been a long time in making contact after the first, causing them to fear that the research had been abandoned. Many expressed the hope that the research would lead to a change in practice by clinicians and/or the hospital system, so that someone else would be spared the suffering that they had endured. Several of the Hospital participants also had expectations of me in terms of my perceived capacity to offer advice as to how they could investigate and take action regarding their AE. I will discuss this in Section 5.9 on Ethical Issues.

5.6: Data Analysis

The interviews were conducted in 2 stages in order to introduce a temporal aspect and to allow emerging themes to be tested with participants. The process of coding used in thematic analysis de-constructs qualitative material, in this case the interview transcripts, in order to discover core themes or meanings. However, it became clear on careful examination of my data that given the nature of much
of it, a further layer of analysis was required. Many of the interview transcripts were rich, dense and full of complexity as individuals sought to make sense of their AE experience. I was keen to ensure that this complexity was reflected by the development of a ‘model’ of the experience of AE and not simply left in the domain of key themes.

1: Thematic analysis
Thematic analysis involves the inductive identification of codes from the empirical data (Liamputtong and Ezzy, 2005, p.192) and the building up of observations and insights as the research is being conducted (Liamputtong and Ezzy, 2005 p.194). I began the task between the first and second round of interviews. I printed off all of the first round interviews and reviewed them by cohort group, reading each of the transcripts several times over. I had a digital recording device in my second round of interviews which enabled me to read the text and listen simultaneously, noting pauses, tone of voice, interruptions of speech, emotional content, intensity and any other personal idiosyncrasies. I also tried to identify what was being left unsaid, or said in a way that suggested political correctness but was at odds with other comments or actions. For example, one of the HSC participants made several references in the interview to the fact that she had “forgiven” the doctor who had caused her AE. She gave me copies however of a sheath of letters she had written to State Government Ministers and the Australian Medical Association demanding that the said doctor be punished. I asked myself what I could have asked the participant, but didn’t. I made notes throughout this initial phase of data analysis.

I then re-read all of the transcripts and using open coding on a line by line basis I noted similarities and differences in the margins of the printed pages. That is to say the data was broken down into discrete parts, examined, and compared for similarities and differences. Those that I decided were conceptually similar in nature or related in meaning, I grouped into a range of categories (Strauss & Corbin, 1998 p.102). For example, a general line of questioning about the effect of an AE produced a variety of responses from participants about their attitude to the AE; the impact of the AE in a life changing sense; the impact of the passage of time; the impact on their family; the lessons learned from the experience; making meaning of the experience; the role of OD; their reasons for making a
complaint; their reasons for not making a complaint; the lived experience of an on-going injury; and the consequences for their sense of trust in the medical profession and/or the hospital system. I was also interested in looking across the 3 participant groups to observe similarities and differences in responses. For example, HSC and VMIA participants had much to say about their experience of the process of lodging a formal complaint or taking legal action: the former had mixed responses, whereas the latter group was universally negative.

The next step in the process of coding according to a grounded theory approach is known as axial coding. Although Strauss & Corbin (1998 p.124), noted that axial coding is not necessarily a sequential step following open coding, my analysis did in fact proceed that way. The purpose of axial coding is to begin to reassemble the data that was fractured during open coding, the aim being to make connections between a category and its subcategories (Strauss & Corbin, 1998). I re-examined my original categories and asked more conceptually based questions of it. For example, many participants spoke about the need for “accountability”. By asking the question as to what constituted accountability, many responses that I had coded under “assumptions about medical culture” became relevant and clearly linked as a sub-category. In another instance, I explored the concept of power and established sub categories of vulnerability, lack of empowerment and life skills and reasons for not making a complaint. In this way, I was able to answer the “when, why, who, how, and with what consequences” type of questions (Strauss & Corbin, 1998 p.125), thereby contextualizing the phenomenon described in each of the categories.

The final step involved selective coding. The aim was to further integrate the categories developed by axial coding around a core concept capable of unifying the data to form a coherent and explanatory theory (Dey, 2004 p.85). As a precursor to this I de-constructed 4 of the main categories, being acknowledgement, accountability, apology and anger, using a diagrammatic format. My aim was to show the component parts and relationships within each. In another diagramme, I sketched out the possible relationships between the categories as a way of clarifying what I thought the core concept to be (Strauss & Corbin, 1998 p.153).
At this point, I decided to use NVivo version 7 as the toolkit for more efficiently managing and accessing my data. In order to do so, I needed to repeat my thematic analysis. That is to say, I re-read all of the transcripts and coded openly and axially, or to use NVivo language, to free nodes and then tree nodes. A “node” is the NVivo term for the categories referred to previously. Free nodes are the receptacles for all of the themes in the data. These were subsequently collapsed into tree nodes which reflected my identification of the linkages and sub categories within a particular category, arranging the data hierarchically. For NVivo purposes, each participant constituted a “case” in respect of which a list of attributes was generated. These included hospital admission history (few/many); age; who complained to (HSC/lawyers); country of origin; gender; location (metropolitan/country hospital); medical condition (ongoing/resolved); prompt for complaint (self/family/friends); and satisfaction (of those who complained, who had been happy with the process).

The key to benefiting from NVivo software is to understand that it offers a relatively easy and flexible way of interacting with the data. For example, I was able to browse all of the data coded at a category and clean it up, if required, in the sense of encoding or moving it to another category (Richards, 2005 p.97). Similarly, calling up and printing off all of the comments about “accountability” and interrogating the data as to what women had to say about “acknowledgement” were straightforward exercises. Attempting to do either of these tasks manually would not only have been extremely time consuming but also more open to error.

The NVivo exercise also acted as a reliability check on my earlier thematic analysis. My coding had been centred on 4 key themes and through the selective coding process of integrating and refining my categories my central category emerged, providing an integrated, theoretical underpinning for my research (Strauss & Corbin, 1998 p.146).

As an adjunct to the coding process, I reviewed 3 transcripts with my Supervisors (LG & TR). There was a high level of consistency with the themes that had been identified in the data, that I had interpreted, and was subsequently confirmed by external Supervisors.
2. **Mapping of participants and creation of a 4A Model**

In order to test my central category and explanatory ideas I developed what Blaikie (2000 p.169) defined as a “theoretical model”. The rationale of my model, that is the central organising idea, was that acknowledgement was crucial for patients who had suffered an AE. The structure of the relationships between acknowledgement and the other 3 key concepts of apology, accountability and anger formed my model (Blaikie, 2000 p.169). I constructed a 4 point shape and placed one “A” at each point, with acknowledgement at the top. I developed 2 map legends on the basis of my NVivo participant attributes, one for the Hospital group and another for the HSC and VMIA groups. Using sheets of A3 tracing paper, I then mapped participants against each point of the 4As, the key concepts, as recorded over the course of the 2 interviews. I used a scale of 1 to 5 to reflect the degree of intensity expressed, with 5 being the maximum. For each group, I identified participants who strongly agreed with the model; those who partially agreed; those who were not inconsistent with the model; and those where there was no apparent fit. My mapping of the 4 “A’s” was very useful. It provided a graphic illustration of participant responses to each of the 4 “A’s”.

3. **Building up the 4A Model**

The Model evolved from a gradual, methodical, and meticulous process involving a series of inquiries of my data. It was a step by step process and each step is explained, and in the order that they occurred.

1: **Creation of a set of Attributes**

I began with NVivo analysis, creating a casebook of participants with background data such as age, country of origin, gender, and whether they had suffered the AE in a metropolitan or country hospital. This was preliminary fact finding and the data did not reveal anything that was noteworthy. I then added further “attributes”, or facts, which I hypothesized could be influential in the way participants responded to an AE. The list below details the attributes and why I thought they could be relevant. In the second part, I explain how it was that, whilst providing useful information, the attributes offered nothing by way of answers about participants AE responses. Rather, the attributes highlighted the need for further
analysis and an alternative schema for understanding the patient experience of an AE.

1. Admission history (few/many: F/M)

Whether a patient who had had few, if any, prior hospital admissions would be more affected emotionally by an AE than a person who had had numerous admissions because of a “surprise” factor given the level of trust in doctors expressed by participants in Chapter 4; conversely whether a history of hospital admissions inclined participants to be more accepting of or “conditioned” to medical error.

No pattern emerged linking the response to an AE with the number of prior admissions. In fact, with the exception of 3 of the outliers, the AE came as a surprise to all participants.

2. Medical condition (continuing/resolved: C/R)

Whether a resolution or reversal (as a surgical procedure) of the AE-triggered medical condition satisfactorily concluded the episode from the participants’ point of view leaving them reasonably well reconciled with the doctor and the care they had received; conversely whether it was only patients whose medical condition remained unresolved that remained angry.

There were 12 participants overall whose AE triggered medical condition had been resolved either by the first or the second interview. Of these, only 3 participants declared themselves to be content with their AE health outcomes: Mark, Brian and Sam from the Hospital group. Nine other participants whose medical condition had been resolved remained angry about there AE. Physical resolution of AE harm was not predictive of participants’ ongoing response to the AE.

3. Response to apologies in various forms including hypothetical ones. For Hospital participants (positive/neutral: P/N); for HSC/VMIA (difference/unlikely: D/U)
Testing the hypothesis as to whether receipt of an OD intervention would be experienced as helpful by those Hospital participants who received it, potentially diffusing anger and likelihood of legal action trial was the purpose of the Hospital trial. HSC and VMIA participants were asked to respond to the hypothetical question as to whether the receipt of an OD and expression of regret or apology would have made them less inclined to lodge a complaint or take legal action.

This was influential for some participants but no clear pattern emerged linking the receipt of an apology or not, as the case may be, as the sole determinant of the type of response made to the AE. Eight of the fifteen Hospital participants had an OD intervention by a doctor who was not their treating clinician. It had little or no effect on participants, and did not influence their response to the AE, though Mary noted that it should have been the responsibility of the surgeon who had operated on her to come and explain the AE and apologize. Separately, three other participants received an apology from their treating doctors. This had a marked and beneficial effect on 2 participants whilst the third rejected it outright. Another 3 participants from HSC and VMIA received and rejected apologies. The hypothetical question put to all other participants about the potential efficacy of an apology, had it been offered, received a generally positive response: Brian, Carolyn, Ros, Christine and Doris all spoke explicitly about their wish for an apology. When closely analysed however, the participants’ expressed wish for an apology per se represented merely the tip of the iceberg of their desire for acknowledgement as a patient who had been harmed and by a doctor they had chosen and/or felt they had a relationship with.

4. Motivation to take action (self/family/ friends/other: S/FF/O)

Whether the source of the motivation to act revealed any difference in degrees of angry responses between participants.

The source of the motivation to take action about the AE did not affect which participants remained angry.
5. Satisfaction with processes (yes or no: Y/N)

Whether participants considered that the formal and/or legal processes embarked upon, including for some receipt of financial compensation ameliorated and/or resolved the AE for them; conversely whether the unhappy and angry participants were those who had failed to achieve this outcome.

There was no association between formal or legal processes embarked upon and the response of participants to their AE. A strongly negative pattern emerged however in terms of how participants experienced the process itself. Only two participants, Wilma and Jennifer, felt they had been assisted by a process (HSC) but neither felt that it negated the significant cost to their lives of the AE. All other participants felt let down in terms of their expectations as to what a formal and/or legal action would deliver for them by way of reconciling with their AE experience.

6. Sought to take action or further action, all groups (yes or no: Y1/N1)

This question, building on Attribute 5, was to test the extent to which participants remained angry about their AE and were prepared to prosecute their case over time.

A successful legal outcome did not assuage residual anger about an AE on the part of any participant. There were 4 participants from the HSC group who took further action: Brian, Carolyn Janet and Vic. Brian discontinued his suit because he was concerned about the financial risks. Carolyn, Janet and Vic all had successful legal outcomes. Vic was content with his outcome though he remained of an angry maybe generalized disposition. Carolyn and Janet continued to rail against their respective surgeons in the second interview, notwithstanding a “successful” outcome. VMIA participants remained angry and frustrated, and having signed a Confidentiality Agreement as part of their legal out of court settlement they were prohibited from publicly discussing or disclosing any details of their case, including the identity of the doctor concerned. These participants agreed to speak with me through the auspices of their law firm.
The thematic analysis of attributes had not explained participant responses to their AEs, but it had revealed key themes of acknowledgement, apology, accountability and anger.

4. Mapping Themes and Plotting Participants

I began by drawing a diagramme for each A by way of a series of lines and boxes in order to de-construct the concepts of acknowledgement, accountability, apology and anger into the constituent parts, as articulated by participants. This is akin to a series of flow charts, Figures 3, 4, 5 and 6, representing participants’ understandings and expectations of each of the 4As. In a second series of diagrammes, Figures 8, 9 and 10, I map participants by group against each of the 4As. In Figure 11, I combine the analysis of participant responses and map against the 4As. Figures 12 and 13 are my final diagrammes reflecting my findings.

My aim was to demonstrate the 4As and illustrate the interrelationship between them. They can be summarized thus: acknowledgement is embedded within both apology and accountability. Acknowledgement of the patient as a person who has been harmed is a key component of what can be called a “good” apology. Similarly, an unambiguous acknowledgement of error by the clinician to the affected patient is essential to achieving a sense that there had been accountability. In turn, apology and accountability are components of an effective acknowledgement: a sincere and heartfelt apology and the sense that the clinician had learned from the mistake and would improve his/her performance going forward. As a result of understanding the interrelationship of the 4As in this way I conceptualized a shape with acknowledgement as the fixed and pre-eminent point against which the other 3 interacted. I then mapped participants and their respective attributes against each of the 4As.

Use of a scale

I used a scale to reflect the intensity of emotion participants expressed about each of the A points, that is to say how much importance and value they attached to acknowledgement, accountability and apology, or how angry they felt. A score
of 1 was the lowest score, and a 5 represented an intensely expressed emotion. Participants with a score of 3 or more on any one point were included in the Model. My aim was to discern the relative weighting participants assigned to each A in order to ascertain how they understood their needs and expectations. By use of the scale, I was able to place participants against each of the A points in a way that was nuanced and revealed ‘how well or to what extent’ participants matched the 4As, rather than recording a simple ‘yes they did’ want acknowledgement or an apology, or ‘no they didn’t’ feel angry style of research result.

5. Testing the Model

I reviewed my mapping of participants outlined above. I created another set of 4A sheets, one for each group, and identified those participants who strongly matched the Model, those who partially matched, and those where there was no match. Twenty eight out of the total of 33 participants either strongly matched or partially matched the Model. There were 7 outliers, all drawn from the Hospital group, who did not fit the Model: these participants, the outliers, are discussed individually in Chapter 9.

All of the VMIA participants strongly matched the Model scoring 4 or 5 on the scale on at least three of the A points. Nine of the twelve HSC participants strongly agreed with the Model also scoring 4 or 5 on the scale on at least three points. Another two participants (Hugo and Germaine) scored 4 or 5 on two of the points. Given their interview responses, I consider that they inclined towards the “strongly agree” classification: certainly they were more emphatic than the “partially agree” description would imply. There was one participant who scored 5 on Accountability and 2 on Anger and nothing else. I consider that Vic fits the “partially agree” category. The Hospital group provided a more complex picture. In the first interview, 4 participants scored 4 or 5 on three points. Another participant scored 4 or 5 on two points. In the second interview, three participants whose scores had been zero or one on all points in the first round, scored 4 or 5 on three of the A points. Another participant whom I had marked at zero on all points in the first interview scored 4 or 5 on two points. I consider that these nine participants fall into the “strongly agree” category. Don, who declined to participate in a second interview because it was “too upsetting”, scored 4 on
Acknowledgement, 3 on Apology and 2 on each of Accountability and Anger. I place Don in the “partially agree” category. In summary, ten of the fifteen Hospital participants either strongly or partially matched the Model.

5.7: Ensuring Rigour and Credibility

In qualitative research, quality is measured in terms of validity, reliability and objectivity (Higgs, 2001 p.55). Each term has a particular and well understood meaning but attempts to apply the same language to qualitative research have led to confusing results (Janesick in Denzin and Lincoln, 2000 p.3930. A more relevant criterion of quality it is suggested is credibility (Higgs, Ibid): that is, recognising that in qualitative research there is no one “correct” interpretation, the question is whether the explanation given of the phenomena being researched is credible (Janesick, Ibid). There needs to be a demonstrable trustworthiness, transferability and confirmability in the research findings (Denzin & Lincoln, 2000, p.22). In earlier work Schutz dealt with the issue of credibility by formulating 3 postulates that he argued the social science researcher had to follow (Schutz, 1962 p.43). The first of these was the postulate of logical consistency. He referred to the need for clarity and distinctness of the conceptual framework and a logical consistency throughout (Schutz, 1962). This is what Denzin & Lincoln refer to as the appropriate matching of the theoretical paradigms underpinning the research with the strategies of inquiry and the methods adopted for collecting data (Denzin & Lincoln, 2000). Liamputtong & Ezzy use the term “theoretical rigour” (Liamputtong and Ezzy, 2005p. 35) to describe the same point.

In this Chapter I have outlined my epistemological and theoretical position. This provided the framework for my research design and the basis upon which I integrated my research questions with the methods used and the concepts employed. There is, I believe, a logical consistency and congruence to the arguments put to support my methodological and data collection choices. Schutz’ second postulate was that of the subjective interpretation of meaning which requires the researcher to search for the meaning an action had for the particular actor (or participant) concerned (Schutz, 1962 p. 24). In their 2005 text, Liamputtong & Ezzy refer to the concepts of interpretive, methodological,
procedural and evaluative rigour. These are very useful concepts, which I employ here to demonstrate rigour in this research. Research has “interpretative rigour” if “it accurately represents the understandings of events and actions within the framework and worldview of the people engaged in them” (Liamputtong and Ezzy, 2005 p.36). In the Chapters that follow, I have made extensive use of quotes from my participants. In this way the participants speak for themselves and a reader of my work is not solely reliant on my interpretation and representation of the data. I also reviewed 3 participant transcripts with my Supervisors (LG and TR) and there was a high level of agreement as to the themes identified and the preliminary interpretations made.

Schutz’ third postulate was that of adequacy which requires that there be consistency between the constructs of the social scientist and the constructs of common-sense experience of the social reality (Schutz, 1962) p.44. The point here is that the interpretation made must be understandable from an everyday, common-sense perspective. This postulate aligns with what Liamputtong & Ezzy refer to as methodological or procedural rigour (Liamputtong & Ezzy, 2005) p.36. There must be an explicit account as to how the research was conducted and how the research findings were arrived at so as to demonstrate evaluative rigour, ensuring that the researcher had not embellished findings and research conclusions. In this Chapter, I have detailed how I gained access to my participants through the agency of the Hospital, HSC and VMIA. I have described how data was collected, transcribed, coded and stored. I have indicated how I maintained a relationship with many participants over time: the extent to which this was valued by participants has been mentioned but will be referred to in more detail in the following Chapters. In the process of developing my 4A model and by mapping participants I conducted a number of thought experiments with alternative aspects and emphasise, actively looking for alternative explanations. For example, I began by hypothesizing that accountability was the key to the AE experience for participants and that that would be the central plank around which acknowledgement, apology and anger would revolve. However, when I undertook the mapping exercise, it became clear that the data did not support such an interpretation. Patton noted that the goal is to find “the best fit” (Patton, 2002) p. 553. and that failure to find strong supporting evidence for alternative ways of
understanding and interpreting the data increases confidence in the conclusions reached. The outliers amongst my research participants are discussed in detail in Chapter 9. I used these cases to reassess my hypotheses and conclusions but the data was not such as to require a fundamental revision.

Liamputtong and Ezzy use the term “evaluative rigour” to refer to the matters that I address in the next 2 Sections, namely the need for ethics in practice and a high level of reflexivity on the part of the researcher (Liamputtong and Ezzy, 1999 p.38).

Being able to demonstrate rigour in the design of and approach to qualitative research confers on the findings trustworthiness (Liamputtong and Ezzy, 2005 p.31) that potentially means the work can be used and the findings applied in other settings. The study is “credible” in other words. In recent work, Liamputtong has recast the language used to describe rigour in qualitative research, but the underlying principles remain the same. The first point is that of credibility and authenticity examining whether the researcher has made a “fit” or a fair representation of the participant in the findings. Reflexivity is regarded as a legitimate way of checking (Liamputtong, 2013, p.25). Transferability or applicability of the research findings to similar individuals or situations is a second consideration (Liamputtong, 2013, p.26). The third term used is “dependability” which essentially asks the question as to whether there is a coherent, observable, pathway for the reader from the methodology chosen through to data collection methods, to analysis and findings.

The last term employed is “confirmability” which requires potentially participant feedback and/ or researcher reflexivity (Liamputtong, 2013, p. 26, 27). Liamputtong continues with the observation that rigour in qualitative research need to soften in it’s approach, not weaken the discipline of research, but reflect the role of people in researcher data gathering and the generosity shown by participants (Liamputtong, 2013). This is not the hard data of quantitative research. Reframing “rigour” in the context of qualitative research, as Liamputtong has recommended, will be important in future research because it introduces the human interaction between researcher and participant as a key line of inquiry (Liamputtong, 2013, p.27).
The rigour that Liamputtong suggested above formed part of my research design and findings, albeit some time beforehand. Rigour involves an ethical and moral obligation to participants to treat them sensitively and respectively, with integrity and honesty. I have a profound sense of gratitude to and respect for my participants. I have been entrusted with their stories, in many instances in the hope that coming out of my research, changes will be made so that someone else will not have to suffer in the way that they did, originally as a result of an AE, and then subsequently through difficult formal processes.

5.8: Ethical Issues

I fulfilled all of the procedural requirements in order to obtain approval to proceed with my research from the Human Research and Ethics Committees (HREC) of the site hospital and the University of Melbourne. The formal approvals were dated the 20th May and 19th August 2002 respectively. In conducting my research, I was also mindful of, and confronted at times by, the ethical issues that arose in a day-to-day sense: what Guillemin & Gillam refer to as “ethics in practice” (Guillemin & Gillam, 2004 p.263).

The site hospital HREC had 2 principal concerns that needed to be addressed prior to approval to proceed was granted. The first related to the potential distress that could be caused to patients and doctors in speaking about an AE. This was resolved in that it was made clear to participants that if they felt that they would benefit from a further discussion and/or counselling about their AE that that would be available to them. Similarly, the Doctors who assisted the study by undertaking the disclosure intervention were able to request a de-briefing session if required.

Of greater concern to the site hospital HREC, which contextualizes the study, was the perceived potential for the study to cause a greater awareness of AE’s and by so doing trigger an increase in law suits against the site hospital and clinicians. Obtaining an explicit indemnity from VMIA, the public hospital insurer was a pre-requisite for the commencement of the exploratory study.

During the course of the research, ethical issues arose which were outside the
formal approval processes. Specifically, in the course of the second round interviews with 2 of the Hospital participants I was asked for advice as to how they could find out what had happened to them that had caused the AE. Further I was asked what avenues were available to them to take action. Both participants had ongoing medical issues as a result of the AE, involving in one case the need to change the dressings on an open wound several times a day. The participant had been advised by the Royal District Nursing Service that new charges were to be introduced for this service which she would struggle to meet out of her pension. This same participant telephoned me several times requesting that I visit her when she was next in Melbourne for a hospital appointment. The social location of both participants meant that they were under-resourced in terms of knowing how to access help or services and they had a limited sense of personal agency.

After considerable reflection, and following discussions with my Supervisors, I provided both with information and contact details for the Office of the Health Services Commissioner. One participant telephoned me later seeking information about law firms and I sent him material that I downloaded from Slater & Gordon’s website. I did not hear from the participant about her hospital appointment, but I had decided that I would not be available to attend.

The ethical position I reached was that it would be unethical to withhold information that I knew may be of benefit to them. Indeed, to deliberatively withhold could have been seen as an exploitive act given the unequal power relationship between us. As Miller noted, “if they have the means to do so, the researcher has an ethical duty to provide assistance to the researched” (Miller, 2000 p.103).

During my interview process, some participants chose to have a support person with them and I have included the spouses of 2 Hospital participants and 2 VMIA participants in my data. The 3 adult children of a VMIA participant asked for an opportunity to be involved in an interview with their mother (interview 34) but did not participate in either the first or second interview with their mother which was a one on one interview at her home on both occasions. I have not included
Robyn’s adult children in my data analysis beyond in a descriptive way regarding the impact of an AE on families. They simply wanted their experience of an AE to be recorded. I had not specifically planned for family involvement when I entered into my Ethics Committee approval processes, and did not seek specific approval for it, though in retrospect it seems obvious that family members would wish to speak on behalf of loved ones who were unable to speak clearly for themselves at the time of my first interview, or indeed my second interview. The voice of the spouse or family member was an enabling one, allowing participants to be part of the study. It would have been ethically inappropriate to exclude family members from the interview process and often practically impossible when I undertook second round interviews in the family home.

The time interval between my two interviews extended unexpectedly due to personal circumstances beyond my control and explained to participants as part of my second interview. All were happy to proceed, though several noted disappointment because they were keen to participate in my study and time had gone by. I was working within the University of Melbourne Ethical Guidelines and Approvals Processes.

**Recognising the “I” and Reflexivity**

The practice of critical reflexion, or reflexivity, requires the qualitative researcher to be attentive to and conscious of “the cultural, political, social, linguistic, and ideological origins of one’s own perspective and voice as well as the perspective and voices of those one interviews” (Patton, 2002 p.65). This involves not only finding and owning one’s own voice, but also authentically representing the perspectives of the research participants (Patton, 2000). The need to acknowledge and monitor my own participation in the research was of the utmost importance given that I conducted 50 in-depth interviews which I coded, identifying themes, and then constructed meanings around them. In the midst of the research, it is impossible not to feel engaged or involved with participants, one cannot be entirely distant and dispassionate because individuals are allowing you as a researcher entry into their lives, talking about and sharing their real life concerns, which requires respect and humility. To put it another way, qualitative
research reports that avoid the pronoun “I” are, in some senses, attempting to disguise the role of the researcher in the research. Rigorous qualitative research is honest about the role of the researcher in the project (Liamputtong and Ezzy, 2005, p.41, Liamputtong, 2013, p. 27). The need to be trusted by participants in the way in which I approached them as individuals, respectful of their stories, was an important aspect of my research and is reflected in the richness of the personal stories that participants were willing to share with me.

My research interest arose in the context of my work as Co-ordinator of Pastoral Care and a grief and loss counsellor at the Royal Women’s Hospital, Melbourne from 1996-2000. In that capacity, I was called upon to support patients in difficulty, most often associated with miscarriages and stillbirths, but not always. On one occasion I was paged to attend and support a patient who had had an emergency caesarean section. Unfortunately, the patient whilst feeling no pain was alert during the procedure and had a complete recollection of the discussion between clinicians including a comment by the Anaesthetist to the effect that “I am losing her”. Whilst the patient and the baby survived, thankfully, I was struck by the patient’s response to two separate hospital based interventions that I witnessed. The first was a robust reassurance by the Registrar that as all was well the patient could essentially forget the incident. The second intervention was a heartfelt acknowledgement of error and explanation by the original anaesthetist. The patient and her partner were enraged by the former and calmed by the latter.

It was this experience that led me to ask what makes a difference from a patient perspective following an AE. I reflected on the personal encounters that had taken place. I brought that memory, along with my experience and perceptions formed over time working with and for patients in a hospital setting to my research. Whilst none of my participants were aware of my background, other than as an academic researcher, I was mindful of the need to critically reflect on the assumptions I was making about my data, and the conclusions that I was drawing from it. I was greatly assisted in this process by my regular supervisory meetings with Professor Lynn Gillam and Dr Therese Reilly (LG & TR).

5.9 Limitations of the Study
The main limitation of the study was the proscribed definition of an AE as required by VMIA. Whilst it narrowed the range of AEs available to the study, it has not compromised my research findings.

5.10: Summary of Chapter

In this Chapter, I have outlined the aims of my research work, explained my methodological choices and discussed the epistemological and theoretical framework that underpins the research. I have given detailed descriptions of my data sample and methods of data analysis in order to locate my research findings within a conceptual framework. In the next four Chapters, I present my research findings, a series of building blocks, leading to conclusions and recommendations, based on the theoretical framework and research rigour documented in this Chapter.
Chapter 6:

The Patient Journey

Introduction

In this Chapter I document both the practical and emotional issues faced by participants following an AE. At the extreme end of an AE experience reported in this thesis it meant loss of sight in one eye, compromised sight in the other for a plumber in his early 50s; a decision by a mother in her then 30s not to have a second child for fear of becoming totally fecally incontinent during pregnancy; and trauma about bowel movements and toileting options for a woman whose job required her to be travelling on the road 5 days a week. These are some of the examples of the long-term consequences of an AE. My intention in this Chapter is to map the breadth and depth of implications of an AE for participants and their families, using direct quotes, in order to give both voice and recognition to the patient/participant experience, and to illustrate the way in which the AE became a feature of their life stories. These are rich stories of patient experiences. However, I do not want the reader to be distracted by the diversity of experiences documented here, or seek to comprehend individual quotes. Rather, hold the thought of the challenges faced, and the steps in the journey taken by a number of participants. I will unpick and unpack the quotes in the course of examining several case studies in the next Chapter. The role of the doctor is central in participant accounts, and the response or lack of response by the doctor to an AE provides the framework for this and the next Chapter.

An AE is a life experience from which some participants recovered, and others did not. An AE is to be distinguished from illness: it is not organic. An AE is something that happens as a result of patients seeking help and for that reason is experienced as frightening and confusing: the level of trust and vulnerability associated with hospital admission is high. The impact of an AE ranges from seemingly medically minimal to life changing, depending on the patient and the
way in which the patient’s life experiences to date frame his or her interpretation of the AE. When something goes wrong, unexpectedly and unrelated to the patient’s underlying condition, the overall impact cannot be measured simply by an objective assessment of the physical harm caused. Other factors come into play in terms of expectations, loss of trust, even a sense of betrayal. The selection criteria set by VMIA for the recruitment of hospital based participants and then applied in the recruitment of HSC and VMIA participants assumed that the AE would have had a low level impact on the patient. As I demonstrate in this Chapter, the assumption was wrong: many participants reported a detrimental impact on themselves and then a ripple effect through their family, friends and work colleagues as they too became involved.

In this Chapter I set out the patient journey in chronological and thematic order according to Groups. I begin with hospital admission and then continue with the AE and initial reactions to it. Next, I document the experience of living with the consequences of an AE post hospital discharge and separately the impact that that has on the family. The responses to the AE in terms of actions taken are then recorded. In the final section, participants reflect on the AE as a life event and its meaning for them, including issues of trust, and their current view of the medical and legal systems.

I begin by introducing the reader to my participants, using pseudonyms, as I did in Chapter 5. There are 33 participants evenly spread across the 3 groups who participated in first round interviews many of whom continued with my study in second round interviews. The final number of participants were distributed across the three sample groups, reflecting participants with a range of experiences who were willing to speak with me a second time, and who were generous of spirit, and offered insights into their AE experience reflected upon, over time.

The Hospital Participants:

There were 15 patients in this part of the study, 5 of whom I described as Outliers.

8 participants received an OD, of whom 6 reported themselves neutral to the
process, and that it had little of no impact on them at the time. There were
different reasons for this including they couldn’t remember the encounter; the
doctor used language they couldn’t understand; the doctor had already spoken
with the patient and he was aware of his condition. 3 participants received a
disclosure of an error which was outside the study, even though they part of the
study group. Jane dismissed it as just words, without a sincere intent. Mark and
Bruce, on the other hand were reconciled with their respective AEs by the honest
and contrite position adopted by their doctors, who provided a spontaneous “gold
standard” of disclosure to their patients who had suffered an AE on their watch.

1. Anthony

Anthony entered hospital, for the first time, under the supervision of a surgeon of
his choice. Anthony’s surgeon spoke with him about a surgical error promptly
and he was accepting of the error. Anthony received an Open Disclosure but it
had no effect because he felt that he had the information he needed to
understand his AE. When I interviewed Anthony in hospital, he was a
disappointed patient but sanguine. Anthony’s perspective changed over time,
between interviews, as he had another AE, same surgeon, arising from the first
AE, which was a condition that remained unresolved when I interviewed him for
a second time, 3 years later. Anthony was waiting for a personal apology and
corrective surgery by “his” chosen surgeon. He had felt that they were “buddies”
and he wasn’t going to lodge a complaint. Anthony was “cranky” about his
unresolved health issues, and wanted an outcome at a personal and physical
level.

2. Ken

Ken had had a number of medical procedures prior to the hospital admission. He
didn’t have an Open Disclosure process. Ken’s wife, a retired nurse, took an
active role in his care in the hospital. They/she didn’t lodge a complaint for fear of
retribution, her concern, and also a lack of energy on her part after a tough time
in the ICU and hospital environment for both of them. Ken, at the time of my
second interview, said he had benefited from his AE, realizing there was still much to enjoy in life.

3. Lionel

Lionel had had few hospital admissions. He received an Open Disclosure when he was back in the Ward after a stay in ICU. Lionel didn’t comprehend the OD, too ill to absorb information, as he reported to me in our first interview. Lionel’s wife was present with him throughout his hospital stay but felt ignored by doctors. The AE, the cause of his complication and ICU stay, remained a mystery to him when I interviewed him a second time, some years later.

4. Mary

Mary had had a number of hospital admissions. Mary received an Open Disclosure and found it helpful in the sense of extra information about her condition, having spent an extended period in ICU, without awareness, apart from the subsequent reporting by her family. The Open Disclosure protocol failed Mary because it did not involve the surgeon who could provide an explanation to her directly about her AE. Mary did not intend to take formal action, but considered that she had been treated “as a piece of meat”. Mary was not available for a second interview.

5. Don

Don had had a number of hospital admissions, awaiting a diagnosis. Don received an Open Disclosure after a surgical procedure led to further complications. Don had no particular response to the Open Disclosure, was neutral to it, but expressed a wish in our interview for better communication between doctors and patients, and more information on an ongoing basis for the patient. Don was not willing to participate in a second interview, explaining in a telephone conversation that discussing the hospital admission was upsetting to him.
6. Carol

Carol had had many prior hospital admissions, but described herself as “surprised” by her AE. Carol did not receive an Open Disclosure but was desperate for information about her condition, and complained that the doctors did not take her into their confidence about what was happening to her, rather talked amongst themselves during Ward Rounds. Carol was very unhappy, angry, about her care when interviewed. Carol died shortly afterwards.

7. Pam

Pam had had many hospital admissions but was totally trusting of, and at the same time, intimidated by doctors and hospitals. Pam did not receive an Open Disclosure. At our first interview Pam was “away with the pixies” to use her term. In our second interview, she was despairing about what to do about an ongoing medical condition, not knowing where to turn. She had not thought of taking action in any form, for fear of retribution when she entered hospital next time, and personal issues of agency.

8. Jane

Jane had had many hospital admissions. When I interviewed her in hospital Jane was unhappy with her hospital care, specifically around pain relief. She complained to no avail, and discharged herself to her own care. Jane did not receive an Open Disclosure. Jane returned to hospital as an emergency admission. The Doctor apologised to Jane for not understanding her condition but Jane rejected the apology as insincere. In between interviews, Jane explored legal alternatives and paid money in order to do so but concluded, after a letter from the hospital, that she couldn’t afford to continue.

9. Mark

Mark had had prior hospital admissions. He did not receive an Open Disclosure as part of the study process. Mark had a spontaneous Open Disclosure, or rather
a personal discussion about a medical error, which was initiated by his surgeon, and the assisting surgeon, who had observed him over his recovery. Mark’s family had observed the attentiveness of the younger doctor and reported it to Mark. Over 2 interviews, Mark was happy with his care and forgiving of medical errors.

10. Bruce

Bruce had had prior hospital admissions, but was surprised and annoyed by his AE. Bruce did not receive an Open Disclosure as part of the study process, but had an explanation and direct exchange with the doctor, which allowed him to forgive whatever had happened, concluding that medical mistakes happen, and importantly, he had been acknowledged by the doctor concerned. Over 2 interviews, Bruce saw no need to take action.

The Outliers

11. Jan

Jan had had a few hospital admissions, but the AE was a shock with ongoing implications for her health and wellbeing going forward. Jan received an Open Disclosure but couldn’t remember anything about it at the time of our interview. In a follow-up telephone call, inviting Jan to participate in a second interview, she declined. Jan said she had had to give up work as a result of her AE, managing her condition was difficult, and she didn’t want to talk about it any further.

12. Roger

Roger had had previous hospital admissions for cancer treatments. Roger was an unexpected re-admission to hospital for treatment and considered that he had been discharged too early. He received an Open Disclosure, which was helpful for him in terms of “layman’s language”. Roger commented on the lack of communication between hospital staff, noting that his chemotherapy regime had not been taken into account in his ongoing treatment. Roger was grateful for his
hospital care, and looking forward to life, including running a marathon, after hospital and cancer. Roger was not available for a second interview and not contactable at his previous address.

13. Justin

Justin had had few hospital admissions. He was surprised but not concerned about his AE. Justin received but was disinterested in the Open Disclosure process, and requests for follow up interviews, including through his main contact person, his sister, were ignored.

14. Elsie

Elsie had had many hospital admissions. She was trusting of the hospital environment and staff. Elsie received an Open Disclosure, after an AE, but it had no particular meaning for her. It was just “more big words”. Elsie was happy with her care. Elsie died a few months after our interview.

15. Sam

Sam had had no prior hospital admissions. Sam was an emergency admission and in his view was saved by the availability of doctors at a public hospital. Sam didn’t have an Open Disclosure. He alerted staff after surgery, back in the ward that he was having a problem, and after a change of staff and continued agitation on his part, a blockage, was fixed. Sam remained satisfied with his care. Sam had a philosophical view of life, considered that he had had a good one, and was accepting of medical error, because as he said, “it happens”.

HSC Participants:

The majority of HSC participants did not receive an OD disclosure. Two participants, Norma and Germaine received an apology and an acknowledgement
of error respectively by the doctor concerned. Norma’s doctor tried hard to convince her of his remorse, but because he attributed the cause of the AE to equipment failure, rather than his personal failure to check, Norma rejected his representations and continued to write letters to people in authority in the health care system, calling him out. Germaine rejected the attempts to explain and apologise, in a similar vein to Norma, because it lacked in her view an acceptance of personal accountability for the harm caused. Germaine went on to take legal action, the outcome of which is unknown.

1. Brian

Brian had had few hospital admissions. He chose his surgeon, and a suggested hospital site which would expedite his procedure. Brian, on a personal level felt embarrassed and humiliated when things went wrong. He considered that he had made a wrong decision in terms of the surgeon, on reflection, and it had proved costly in terms of his hearing loss. Brian contacted the HSC, found the process adversarial, with no acknowledgement from the Doctor. Brian started a legal action but withdrew on the basis of potential costs associated with a failed legal action.

2. Carolyn

Carolyn had had few hospital admissions. She entered hospital for routine surgery, at a hospital where the doctor had visiting rights and offered her an expedited service, having noticed her name on a public hospital waiting list and contacted her. The procedure went wrong, the doctor refused to attend afterwards, or acknowledge an error. Carolyn contacted HSC but did not find the agency helpful. Carolyn took legal action and won her claim against the doctor.

3. Wilma

Wilma had had few hospital admissions. She entered a major public hospital for elective surgery. Following the surgery, Wilma suffered 4 years of pain before another surgeon performed corrective surgery which was transformative for her
physical and mental health. Wilma contacted HSC and found the agency helpful as an ally when dealing with hospital bureaucracy, against which she felt personally powerless.

4. Jennifer

Jennifer had had many hospital admissions, following a cancer diagnosis. After prior failed medical procedures, Jennifer found a second surgeon who believed her story of pain and discomfort. Jennifer contacted HSC and found the agency helpful but concluded that it was only with the pictures taken, and supporting comments by surgeon 2, that the agency paid attention to her.

5. Janet

Janet had had few hospital admissions. Janet understood she had had an AE when she was airlifted from a regional to a metropolitan hospital. In a follow up consultation, her treating doctor was, from her point of view, dismissive of her. Janet contacted HSC, but was not satisfied with the efforts of the agency. Janet took legal action and won her case against the doctor.

6. Fiona

Fiona had had hospital admissions, the number of which I am not sure. Fiona felt “fobbed off” by doctors. The HSC process gave Fiona an opportunity to be listened to, including by me.

7. Anna

Anna had had few hospital admissions and described herself as “very healthy” until her AE. Anna consulted her GP about pain and entered a rural hospital for a relatively routine investigative procedure, performed by a surgeon connected to the GP practice. The failed procedure resulted in Anna in Intensive Care. Anna contacted HSC, but the process also failed her because she never heard from the
surgeon.

8. Norma

Norma had had hospital admissions for cancer, but on this occasion it was for a different diagnosis. Norma received an apology for a failed procedure by the doctor concerned. Norma rejected the apology because the doctor did not take personal responsibility rather attributed her injury to equipment failure. The HSC process brought attention to her complaint, but did not resolve it.

9. Hugo

Hugo had had few hospital admissions and whilst English was his second language, he had been resident in Australia for many years. Hugo declined a second operation at the hospital site where he suffered an AE, preferring to stay on the waiting list for another hospital. HSC advised they could not assist, until after tests associated with a second operation.

10. Len

Len had had many hospital admissions. His wife was his spokesperson following the AE. The HSC process proved to be unsatisfactory and between our interviews, Len had taken legal action, seeking financial compensation. The outcome was unknown at the time of our second interview.

11. Germaine

Germaine had had many hospital admissions. She received an acknowledgement of error by the doctor during the hospital stay in question. Germaine rejected it as insincere. After making contact with the HSC, Germaine concluded that the process was tied up with the Hospital system and she didn’t expect a just outcome. Germaine was taking legal action at the time of our first and only interview, the outcome of which is unknown.
12. Vic

Vic had had few hospital admissions. He was unsatisfied with the HSC. Vic took legal action, the Hospital concerned admitted error, and he received a compensation payment for surgical error. Vic considered that words weren’t important. He had received a settlement and that was the end of the matter.

VMIA Participants:

Two VMIA participants received information about their AE.

1. James

James had had few hospital admissions. James was the only VMIA participant to receive a form of apology from the doctor concerned with his AE. James dismissed it as a form of words which he did not hear as sincere. It was an angry and painful process for James. James suffered a serious injury. The doctor concerned offered him a form of words which James heard simply as formulaic, and without an underlying sincere intent, or concern about him as a patient who had been harmed on his watch and who he had trusted. The words of “apology” delivered in a particular way did not constitute a “proper apology”, nor did he consider that the doctor had been held accountable.

2. Ros

Ros was very surprised by her medical error and her family very distressed at the time of her original hospital stay by the lack of responsiveness to her needs by the surgeon in charge of her case. Ros was subsequently transferred to a tertiary hospital where she recovered. Ros took legal action, and received a settlement
but did not consider it a win, because the legal process did not provide what she wanted, which was acknowledgement by and accountability of the doctor.

3. Christine

Christine had had few hospital entries but a long standing relationship with the gynaecologist who had delivered her daughter. Christine had continuing concerns after a failed diagnosis and surgical treatment which has resulted in life long suffering. The legal process did not alleviate her psychological suffering because the doctor was not held to account, and importantly, after a long standing relationship, did not contact her to acknowledge her AE, and apologise.

4. Margaret

Margaret had very few hospital admissions up until the birth of her first and only child. The delivery went wrong and whilst her baby was safe she suffered severe ongoing injuries. Margaret spent time, energy and money trying to understand the nature and cause of her injury. When she did so, she came up against the medical collegiate would not testify against one of its own to support her claim. The legal process she entered into was a roller coaster ride into unfamiliar territory, and with no net end benefit. There was no acknowledgement, apologies or even explanations from the medical establishment of her rural community.

5. Michael

Michael was told by a doctor who had not been involved in his hospital care, that he couldn’t understand how the AE could have occurred (a swab was left in Michael's abdomen). There was no satisfaction for Michael in this encounter because it did not involve the presence of, or an acknowledgement and apology from, his treating doctor. Michael’s strong sense was that there was a desire to hush up his AE.

6. Doris
Doris had had hospital admissions associated with cancer surgery, but this one occurred after a relatively simple accident in the kitchen where she sliced herself with a knife. Doris and her husband were admitted to the emergency department of the local hospital where she was treated. Regrettably, there were complications which required surgery and physiotherapy. There were no apologies forthcoming from the hospital, which was a source of regret for the couple, but they hoped that by making a complaint, someone would sit up and take notice about hospital practice and procedure.

**Before the AE – going into hospital**

A person who has suffered an AE during hospital stay and survived began their journey on the usual patient trajectory of not knowing but trusting in the doctors and the hospital institution, as discussed in Chapter 4. The passive patienthood role is the usual emotional point of entry to a hospital. Parsons identified as early as 1951 that there was an “asymmetrical” relationship between patients and treating doctor(s) (Parsons T, 1951, p.33) when a person was admitted to hospital. The patient had received a diagnosis of an illness, or a condition had been identified that required hospital based treatment. Of necessity, the patient is reliant upon the treating doctors and the hospital system to keep them safe and to assist them to get better. For most people however entry into the hospital environment is akin to visiting a foreign country without having any language skills. Simple, yet symbolic, acts such as being given a UR number for identification purposes, disrobing, getting into hospital gowns and booties, if a day procedure, or straight into bed if there is to be a longer hospital stay, are reminders to the patient that he or she is no longer in charge of his or her life. In physical vulnerability, as with life generally for some participants, there is a sense of powerlessness. Life has become disordered. There is only one practicable response for a patient and that is to trust that one is in safe, professional hands, and will receive appropriate medical care. All participants had this expectation and it applied irrespective of whether there had been a prior relationship with the treating doctor or not.
The extent to which the hospital setting was felt to be foreign, potentially alienating, was remarked upon by participants.

Mary was one of the patients on the surgical rounds list of a senior doctor which meant that her bed was surrounded by a group of junior doctors one of whom would have been required to give a structured presentation of her medical history and diagnosis in front of the senior doctor and peers. Ward rounds are an essential part of clinical training for junior doctors, part of the tradition of medical education through the acquisition of a “medical gaze”. What was routine for the medical team lacked context for Mary. It was experienced as depersonalizing, and Mary’s attempt to join in the conversation about her care by asking questions was largely ignored.

“I just felt like I was a piece of meat, not a patient but just a piece of meat that they discussed when they felt like it, and answer questions when they felt like it”

Mary; 63; Hospital: 1st interview

Carol was also disappointed that the doctors did not engage with her on a personal level and take her into their confidence, as it were, about her health care. Carol felt excluded from information about her physical state and from the decisions being made about her. If she knew more, if she was brought into the inner circle she could be more trusting because trust is built up through relationship. Carol, like Mary, metaphorically reached out for relationship or a partnership with the doctors to no avail.

“They (the doctors) don’t seem to tell you anything or give you a suggestion of what they may be doing until just a moment before. Instead of just rushing in and out they could confide in you a little bit more and that would give you more trust in them”

Carol; 65; Hospital: 1st interview.

Another participant, an ex nurse used to working in hospitals, found that her adult capabilities drained away when she admitted as a patient, leaving her feeling powerless:
“You lose all sense of being in control in a hospital. You don't know what’s going on.”

Ros; 60; VMIA: 1st interview.

The Adverse Event

1: Immediate reactions

The Hospital participants were interviewed at the closest point in time to their AE. They came to know about it, theoretically, as an AE if they were in the OD protocol group, although several could not comprehend what was said to them at the time or recall it afterwards, raising questions as to the timing and content of an OD intervention given a patient’s condition and capacity to process information. Other participants came to understand that there had been a complication arising from their initial procedure because of the need for further surgery, an ICU admission and/or a protracted hospital stay. Whilst participants may have been surprised, disappointed or annoyed that something had gone wrong with their care, the overall reaction was one of relief that they had pulled through a medical crisis.

Lionel was admitted with spasms of pain in his stomach which turned out to be an ulcer on his colon. There was a total wound breakdown 8 days after surgery necessitating further surgery, 2 days after which he suffered acute renal failure and was admitted to ICU. Back in the ward Lionel received an OD which, whilst confirming for him the seriousness of his condition, did not help him understand what had gone wrong. This was still an open question for him 3 years later when I interviewed him a second time. However, in the immediate aftermath, Lionel was philosophical:-

“I didn’t realise I was that low. Intensive care frightened me. It’s (AE) just one of those things that had to happen. Well it didn’t have to happen but it did happen”.

Lionel; 65; Hospital: 1st interview.
Jan was admitted for a hernia operation but deteriorated afterwards. A second procedure revealed an obstruction in her bowel resulting in her being fitted with a stoma. Jan received an OD but such was her sense of shock and confusion she had no recollection of it. Overwhelmingly grateful to be alive, though not understanding how she came to be in this position, Jan was apprehensive as to how she was going to cope with the stoma when she went home and back to full-time work (notwithstanding the possibility of it being reversed in 6 months time):

“It’s a shock that one minute they say you’re fine and the next I’m all knotted up inside and in intensive care. I thought once I had that operation (hernia) everything was fixed. It’s just when you go home you have to stick with it (stoma maintenance). What can I do? I’m walking around here (alive) that is the main thing. Like, I might not have been”.

When asked to rate on a scale of 0 to 5 how happy she was with the care she had received, Jan replied:

“I would take it to 5, because I can’t complain about anybody since I’ve been here. They have all been helpful, good to me”.

Jan; 61; Hospital: 1st interview

Bruce was diabetic, and admitted for elective surgery for an obstructed pancreatic duct. After surgery and an initial good recovery, Bruce’s condition deteriorated rapidly. One of the doctors came to him, not part of the OD study, and told him that a mistake had been made, the wound was oozing and needed a complete resuturing: a second operation was required. Bruce was “annoyed”. It was not a feeling he was prepared to share with his doctor, but talked about with his family. However, Bruce appreciated being informed about what had happened, and he moved emotionally from being annoyed to being entirely satisfied. That was the end of the matter for Bruce: let’s just get it fixed. Bruce was entirely satisfied and thankful for the care received, a view he reiterated in an interview 3 years later.
“Yes good or bad, tell the truth, what’s going on, what’s happened. Everybody make mistakes, especially the doctors, they’re tired, working late. But I mean the doctors do the best that can be done. The operation was a mistake, that’s everything for me. I’m not going to shout why you did that, it’s happened”.

Bruce; 48; Hospital: 1st interview.

Anthony, a 38 year old first time hospital patient, was admitted with diverticular disease requiring a section of the bowel to be cut out and then the whole rejoined. The wound did not heal causing an infection. In a second operation Anthony was fitted with a colostomy bag, a procedure that could be reversed in 6 months. Anthony received an OD, which he characterized as “more of the long words they use”, but felt that he already had a good understanding of what had happened from his surgeon, whom he had consulted pre-operatively and chosen to be his attending surgeon. The surgeon had also explained the risks associated with the procedure.

Anthony had been “scared” by the AE but his reaction was pragmatic, if somewhat rueful. He admits to being “disappointed” but was actually quite “burnt” by the experience. Whilst he decided that it was best not to make a fuss about the AE, he ponders about it from his life experience perspective and finds the doctor’s articulation of risk wanting, a way of shifting responsibility it seems. The priority for Anthony was to get his condition fixed without a “saga”.

“I was aware that there was a 3-5% chance that this could have happened. So how do I feel? Probably disappointed. The “why me” sort of syndrome. Pretty burnt. I could winge and carry on but that wouldn’t get me too far. It’s just one of those (things), that’s what small percentages are made up of (but) I think if they have got small percentages they’re the percentages that have got to be set up to make sure they concentrate on them. That’s the bit I don’t understand. If you’re a painter the internal corners are always the hardest to paint. You think I’ll start with that first, concentrate on those. That’s how we tend to work in the building game. I mean Paul (surgeon) explained things (risks) but it leaves a nasty taste in your mouth going into theatre. If I was buying a used car or taking a car into
be fixed, I expect a warranty. And this is about my body! Hey, they (doctors) can't jump back into their comfort zone and try and cover themselves completely”.

Anthony; 38; Hospital: 1st interview.

2: Discovery over time

Only one of the HSC participants and one of the VMIA participants understood that they had suffered an AE whilst they were still in hospital. In the first case, the treating doctor apologised and explained that a faulty piece of equipment had caused an injury to her throat (Norma). In the VMIA case, one of the doctors involved in the participant’s care, but not the treating doctor, informed Michael that a swab had been left in his abdominal cavity after heart surgery causing serious post operative complications and the need for further surgery.

All the other participants discovered that they had suffered an AE through persistent efforts over time to understand why they continued to be unwell or have some physical manifestation that was unusual and causing distress. The typical pattern for participants was to return to their initial treating doctor many times over, sometimes years, seeking an explanation and understanding of their condition (Jennifer, Christine, James, Wilma, Brian, Margaret/GP). The typical response by the doctor concerned was to dismiss their concerns, to deny their experience, saying that the symptoms were to be expected and would settle down over time (Wilma, Jennifer, Christine, Brian); to suggest that the problem was in the patient’s head (Jennifer); to fail to diagnose correctly (James); or simply remain silent in the case of Margaret’s’ referring GP (Margaret/GP). This is consistent with the different perceptions of illness, and the impact of illness on a patient, as between patients and doctors as discussed in Chapter 4. It is worth noting at this juncture though that the patients I am discussing suffered an AE, on top of an illness.

The extent of denial by some doctors of patient experience is illustrated in the case of Wilma who entered hospital for a full right hip replacement and emerged with an operated leg 2.5 cms longer than her non-operated leg. On
her return visits to the surgeon, complaining, distressed, she was assured that all would come right:-

“He said “oh these things settle down and it won’t be very much at all, it won’t matter. And I kept saying, it feels like it’s lots, and he kept saying no, no, no, it’ll settle down”

Wilma, 64: HSC: 1st interview.

After much frustration, participants sought a second opinion and with that their suspicions or conviction that something was amiss with the original procedure was confirmed (Jennifer, Christine, Margaret). Other participants received a second opinion by circumstance (Wilma, Ros, James) through a change of Head of Orthopaedic Surgery (Wilma), through an emergency transfer to another hospital (Ros) and a GP intervention and referral for a second opinion (James). Ros, through the Freedom of Information Act in Victoria retrieved her medical history files that confirmed she had suffered an AE, though she and her children already knew that. James collected his medical records personally from the doctor who failed to diagnose his condition and was shocked to read that the doctor nine months into consultations had recorded him in patient notes as being psychosomatic.

Jennifer had breast cancer at the age of 47 and two years after surgery decided to have a breast implant following which she experienced a great deal of pain, had difficulty lifting her arm, and was unable to get comfortable on that side of her body in bed. Jennifer felt that the implant was too tight and went back to the surgeon regularly over a twelve-month period. Lacking medical expertise, Jennifer found it difficult to argue against the surgeon who assured that all was right and offered her a script for sleeping tablets instead. Finally, Jennifer consulted a new GP and obtained a referral to another surgeon who confirmed Jennifer’s self-diagnosis.

“I was feeling very apprehensive when I went to him but came away feeling great when he asked me what I thought was wrong and I told him and he said ‘yes you’re perfectly right’ and at that stage I just burst into tears because I thought for the first time in twelve months someone believes me”.
Jennifer was angry about the AE, and with the surgeon, because of the pain suffered, the time wasted with him, and the hoped for restoration of self and body image that she had invested in the implant that came to nought.

“It (AE) was a more significant event in my life than the actual cancer. With the cancer I felt it was something beyond my control, but with having the implant put in I thought I was taking control of my life and to actually come out worse off than what I was before I had it done…I was really cross with him that he couldn’t admit that it wasn’t right. I mean he just kept telling me that it was all in my mind”.

Jennifer; 57; HSC: 2nd interview.

3: Living with the Consequences of the AE

The full impact of an AE is felt in the lived experience and for participants from all 3 groups, it was life changing: negatively for the majority, a mixed blessing for a few. The three-year and one half year time lapse between the first and second interviews brought the continuing Hospital participants broadly into alignment with the HSC and VMIA continuing groups in terms of temporal distance from the AE. My participants’ life narratives were changed by their AE. The literature about illness and the personal experiences of illness have been framed by Frank (1995; 1997; 1998). Frank’s observations about illness, and drawn from his personal experience, remain relevant reference points in order to understand the impact of an AE on a patient, and the way in which my study participants responded to an AE. There is a strong correlation because life was never the same again, but potentially an AE has a more profound impact, drawing into question taken for granted assumptions about how the world works, the external factors and agencies in play, and one’s sense of self and identity in the overall picture. The AE experience is contiguous with that described by Frank about patients suffering an illness. Participants described a diminished life in the following way:

Lionel was off work for 6 months following his AE and lost his job as a result. Ongoing, persistent diarrhoea provided a constant reminder of the
AE and diminished his quality of life as he explained:

“It’s affected my whole life. I mean I’m a bowler and I can’t go out on a bowling green all in white in case all of a sudden I’ve got an attack of diarrhoea”.

Lionel; 65; Hospital: 2nd interview.

Jane was admitted with a suspected cyst. Complaining of intense pain, her treating doctor was sceptical and Jane discharged herself saying that she had better pain killers at home. The cyst burst and she was an emergency admission. High levels of steroids were used to stabilize her condition which Jane attributes to the onset of osteoporosis and an overall decline in her health:

“I get quite passionate about it (AE) because I do blame her (treating doctor) for me not being able to work. I nearly lost my house because of her, because I couldn’t go back to work. We had to refinance. It all snowballed from that (AE) and had a huge effect, not only on me but my family. I mean here I am in the afternoon still in my pyjamas because my back’s gone because of all the frigging drugs that they’ve had me on and now I’ve got soft bones. I had a good job. I had everything, now nothing and that makes me angry. I don’t like being stuck here not working. Before I was a normal person: I’m not now”.

Jane; 48; Hospital:2nd interview.

In the immediate aftermath of the AE, Jan had begun to muse as to how she would cope with a stoma when she went home and back to work. Three years down the track, when I contacted her for a second interview, Jan declined saying she did not want to talk about it (the AE), adding that she had had to give up her job. It seems reasonable to conclude that the lived experience for Jan had proved to be very difficult.

The failure by his neurosurgeon to read the original carotid artery duplex scan led James to be treated for a range of misdiagnosed conditions. When a second neurosurgeon identified this fact James was in a grave situation. Emergency surgery could not save his sight in one eye and only just managed to preserve
limited vision in the other. James had worked as a plumber for all of his adult life but now at the age of 52 was in fear of losing his job because of the constraints imposed by limited vision:

“I’ve never had any obstacle that I couldn’t get around but now I get stressed out because I can’t see it and then I worry that I’m going to lose my job because I’m slower. It takes me a lot longer to do things because of the sight problem. I can’t work the same because simple things like arc welding I can’t tell with perception of depth. Underneath benches, sinks and basins, anything that blocks my left eye, the good one, and if I can’t get my head any other way around, I’m gone because I can’t see”.

James; 52; VMIA: 1st interview.

The disparity in the length of her legs meant a complete change of lifestyle for Wilma and constituted a significant challenge for her physical and mental well being. Every day was a reminder that she had suffered an AE. Wilma had been an active sportswoman before the hip replacement operation but had been forced to give that up. She now had to have specially built up shoes.

“The legacy I’m left with is that my self-image is pretty awful because I used to be, you know I used to think that I was alright…so athletic. I have constant pain in the hip and leg and so I don’t sleep well. I’ve been clinically depressed for a little over a year. I’m used to being very active and it concerns me that I’m in physical as well as like mental discomfort because with this I feel ugly and there’s only limited shoes that you can have built up. I’ve stopped crying every night and I’ve stopped feeling totally sorry for myself but it (AE) has made me feel 10 times older than I really oughtto”.

Wilma; 64; HSC: 1st interview.

The joy of a first pregnancy and child birth were overshadowed for Margaret when instead of doing a standard episiotomy the obstetrician cut through her anal sphincter muscle and an anal fistula developed. It took 2 years and 3 surgical procedures before the mistake was diagnosed and partially rectified though
Margaret was aware that further surgery would be required at some point in the future, if she could summon the courage.

“All I knew was all of a sudden I’m squeezing this muck from another hole to my bottom that I didn’t have before and it was causing me an enormous amount of grief. I couldn’t walk down the street without it sticking and thinking, oh God, I’ve got to find a toilet so that I can deal with this. So I was in pain for something like 2 years of my life and also because my body kept reinfecting, it was draining all my energy all the time. I mean sex went out the window and natural things like that. You know things that you take for granted are no longer part of my life because I just couldn’t bear it.”

Margaret; 40; VMIA: 1st interview.

Christine consulted her trusted gynaecologist whom she had known for 20 years complaining of debilitating menstrual pain. Medication was prescribed but it failed to relieve her symptoms, and it was agreed that a partial hysterectomy would be performed. Post-operatively, Christine suffered a massive haemorrhage and was taken back for emergency surgery. During this procedure, the gynaecologist observed that Christine’s bowels and bladder were tangled together in some way and he surgically attended to it. Over the course of the next year, Christine visited the gynaecologist many times complaining of immense difficulty and pain associated with bowel movements but was assured that “it was a very big operation so it’s going to take a long time to heal”. In desperation, she sought a second opinion resulting in another operation during which both ovaries were removed because haematomas had formed and attached themselves. It was further discovered that her bowel had been damaged. Post-operatively, Christine was advised that she would only get relief if she had a colostomy and a stoma fitted. She refused, and as a result has suffered pain daily.

“Very unhappy memory. Been a nightmare. My life never the same anymore. Never been the same. I have trouble every day because of what Doctor X did. For the first 3 years after the operation I wanted to kill myself. Many times I thought to drive the car off the Westgate Bridge: the pain was so bad. I mean before you use the bowels you have pain like this 2 hours before and then after
you use the bowels you can’t even sit comfortably for about 2 hours so you go for about 4-5 hours every day, the same pain. I was such a healthy person you know and having this (supposed) small operation you turn your life inside-out. It’s a life sentence.”

Christine; 50; VMIA: 1st interview.

Pam, in her mid 70’s, entered hospital with a bowel obstruction and a colostomy bag was fitted during surgery. Infection set in after a second procedure to reverse the colostomy and Pam did not regain her health, indeed lost half her body weight. Pam struggled with both the colostomy bag and an open wound that required dressing changes every day. She was completely reliant on the Royal District Nursing Service to do this and having been notified of a proposed increase in charges was worried that she would not be able to afford it out of her pension. Pam was despairing, not knowing where to go or what to do in order to find someone who could help her. She had been told by the surgeon that she could not survive another major operation. In my second interview with Pam she lamented that she was no longer physically able to look after her husband, who had dementia, and had reluctantly placed him in a nursing home:-

“It’s (AE) has really ruined my life. I couldn’t even have my husband home any longer and that’s dreadful, that kills me. Yes, it’s really ruined my life”.

Pam; 74; Hospital:2nd interview.

Significant life challenges following the AE were also experienced by Janet who was left with a numb leg; Brian, who suffered a hearing loss; and Anthony who had mood swings, and found dealing with a stoma “icky” leading to personally embarrassing occasions.

4: Impact of AE on the family

The studies described in Chapter 4 have a particular focus on the patient experience of illness and of being a patient in relation to doctors and the hospital institution. The literature does not address the impact of a family member’s
illness on immediate family and friends. In my study I discovered that there is more than one casualty in an AE experience. There are ripple effects. The impact of an AE on family members has not been reported previously. The family or friends network, assuming that one exists, ultimately shares the burden of an AE. In the course of my interviews, some family members were present and contributed as they saw fit. Generally speaking, the family was as innocent as their loved ones in terms of a sense of shock and distress about an AE. Whilst there may have been questions about the cause, the family was also typically caught up and out by the immediacy of the situation and their reliance on health care professionals for information.

A number of family members complained about the lack of interaction with and communication by doctors as a source of particular anxiety and isolation. Lionel’s wife Lenore, describing his weeks in intensive care as a “long haul”, spoke of the many instances where doctors came in and spoke with other doctors who were on duty:-

“You weren’t told anything after they had the discussion. They just walked away. I felt they were discussing his condition and what was going on but they didn’t come over and explain to me.”

Lenore; wife of Lionel; 66; Hospital: 1st interview.

Michael said his wife had become distressed as she witnessed his deterioration after surgery but her concerns were dismissed by staff:-

“She knew that there was something wrong and she kept on asking and they said ‘oh no everything’s alright. He’s just getting over (the surgery). He’s got a bit of an infection’.

Michael; 49; VMIA: 1st interview

“I was tired. I was weak and (had) bad pains in the stomach. I couldn’t see what I looked like but she could. I was wondering why she was crying. And they (hospital staff) said ‘oh, you’re wife’s not handling it (his operation) too
well. We’ll see if we can get some counselling for her. This operation’s been
too much for her.’ Yes everyone suffered a bit from it (AE).”

Michael; 49; VMIA: 2nd interview.

Ros, a relatively recent widow, entered hospital to have her gallbladder taken out
and suffered 2 AEs. First, her bile duct had been cut during surgery though this
remained undiagnosed for 2 weeks post discharge, despite a number of
presentations back to the hospital and to the surgeon complaining of acute
abdominal pain. Ros was given pethidene injections and on one of the hospital
visits it was noticed that her blood pressure was high and another drug was
prescribed. Ros queried the drug, saying that she was allergic to it, but the doctor
approved it and she was “too sick to argue with them”. Ros subsequently suffered
3 cardiac arrests and was transferred to a tertiary public hospital where she had
emergency surgery and was admitted to ICU for several weeks. Ros’ 3 adult
children were shocked by the turn of events, frightened that they would lose her,
and enraged by the attitude of the surgeon who wouldn’t listen to their concerns.
After my first interview with Ros, her children expressed a wish through Ros to
meet with me, to tell me about the AE from their point of view and how it had
affected their family. Naomi, the eldest and only daughter, explained:

“I’ve been in hospital for pretty much day procedures and always had positive
experiences. So I came into it (her Mother’s operation) with a fairly positive
attitude that the right thing would be done and that she would receive the best
possible care. I had fairly high expectations that things would run smoothly. I
know Mum was quite nervous but I wasn’t really nervous at all. We were involved
in reassuring her that it was a normal procedure and nothing very serious.Having
come out the other side of it (the AE), I wouldn’t send my dead dog to (name of
first hospital).I reckon the worst part was walking into ICU. That was horrific. Just
to walk in and see her exactly the same way Dad had been (he had died in ICU
following a car accident the previous year). I was beside myself. That was pretty
stressful. I think the whole experience was stressful, but that was particularly
upsetting.”
Naomi’s frustration and anger, 5 years after Ros’s AE, were still very close to the surface and easily vented:

“I was furious because of the whole god sort of attitude; that he (surgeon) was so superior and wouldn’t listen to our concerns. I mean we know our Mother and we knew how much pain she was in. And then the hospital gives her drugs that she told them she was allergic to and she has 3 arrests! I saw him (surgeon) in the supermarket and I wanted to kill him.”

Naomi; daughter of Ros; 30ish; VMIA: following 1st interview.

Her brother Martin recalled the night Ros had the cardiac arrests as they waited anxiously by her bedside for the doctor to come in. Of their subsequent conversation with the doctor, Martin said it was like “talking to a brick wall”. Martin posed a theoretical question for his siblings: ‘can we hit him?’

“My biggest memory was that the junior doctor was yelling at him ‘you’ve got to come in’ and from our perception of the other side of the telephone call it was ‘oh really? Do I need to?’ There was no ‘ok cool. I’ll see you soon’. It was like more of an exchange going on”.

Martin; son of Ros; 30ish; VMIA: following 1st interview.

James’ spoke of the AE as having been a life changing experience for the whole family: ‘Judy tells me that I’m different to what I was and I don’t disagree with that’. For her part, Judy described her reaction to the AE as one of anger tinged with a desire for retribution:-

“When I first discovered that it (AE) was completely preventable and that he (specialist) had made a grave error, I have to tell you I’ve never normally been a violent person but I wanted to meet this man. You know he’s (James) is still alive, so that’s fine (but) such fierce anger that the system let us down. It really really let us down.”

Judy, wife of James; 52; VMIA: 1st interview.
The emotional burden borne by the family was also referred to by Christine, Anthony, Cathy and Wilma. It took 6 years for Christine to learn how to “manage” the intense pain associated with bowel movements following the AE. During this time, she had often contemplated driving off the Westgate Bridge. She had “begged” her partner and her daughter to help her commit suicide. Looking back, Christine said she was sorry for placing them in such an invidious position: ‘when I was in a lot of pain, they couldn’t bear to see it’. Similarly, Wilma who after many years had a good resolution of her AE commented on the relief felt by her daughter who had witnessed the constant pain that Wilma had endured from August 2001 until February 2006: ‘she says she could cry with how good I am (now) compared’.

Anthony admitted that he took out his anger and frustration about the ongoing ‘saga’ of his AE, first being fitted with a colostomy bag and then suffering a hernia as a result of the procedure to reverse the colostomy, on his wife. He was reminded daily of his AE, merely by looking in the bathroom mirror. He thought about what might have been an even worse case scenario. Presumably, after the first AE, Anthony’s wife would have been very sympathetic of his situation, but living with the consequences of the AE for 3 years proved testing for both of them.

“Who do I go cranky at? I mean it’s not Fiona’s (wife) fault and she’s probably copped more than anybody else. Like I say to Fiona, and she’s sort of like ‘well sort of get over it’. You’ve got to learn to get over it and you sort of think, well you’ve never actually been through it. I mean it’s something as severe as your life and it doesn’t just affect me. It affects your family and everything else. I mean it makes you sort of think. You could have 3 orphans on your hands. You could have 1 widow, 3 orphans. What would life be for them now?”

Anthony; 41; Hospital: 2nd interview.

Brian flagged that his two daughters were impacted by his AE because of his changed, more cynical, view of the medical profession. They would learn from his example.
“My daughters will be growing up on the strength of the experience of their parents and they will now see their father not so much suspicious of the medical profession but certainly not taking it for granted. Indeed we had an accident in the car recently and my daughter was a little hurt and when we went to hospital she found me absolutely questioning the doctors, to the extent where (I said) ‘no I don’t think you’re right; I think this is what it is. Could we check this?’ In the past I would (have) just sat back and passively allowed the doctor to do stuff. I guess I grew up in the Ben Casey era and I’m now living in the House era.”

Brian; 41; HSC: 2nd interview.

At a very practical level, Pam’s twin Betty became used to doing a 400 kilometre round road trip to visit her in the country when she was “down”. Betty knew from Pam’s voice when she needed support and was unstinting in giving it. It was a considerable journey for anyone to make, but arguably more arduous for a woman in her 70s.

Whilst an AE journey is unique to the individual, family members are inevitably fellow travellers.

5: Responses to an AE: Inaction, Action, and Perceived Outcomes

Inaction

Participants had different ways of responding to their AE, which turned on personal capacity, agency and resources. Hospital participants as a group, with the exception of Jane, did not complain about their care. When I interviewed them the first time, many were feeling very vulnerable, quite overwhelmed, by their physical condition and aware of their complete dependence on doctors and the hospital at that point in time. It did not predispose them to complain (Jan, Elsie, Lionel, Carol, Ken).

Anthony, Pam and Ken’s wife Maureen worried that there could be repercussions for them, acts of retribution as it were, if they expressed dissatisfaction with the
care provided. These participants broadly fit into the Parson passive role model (Parsons, 1951).

“I don’t like doing that (making a complaint) to doctors. If I wanted treatment there again, I probably wouldn’t get it and stuff like that. Like if I got rushed back or anything they might push me aside or something you know?”

Pam; 74; Hospital: 2nd interview.

“Well I could have made a complaint to (the Hospital). I don’t know where that would have got me. In this day and age, I’d think it was sour grapes and next time I’m on the (surgical) table, it would be a case of ‘here’s that bloke who whinges’. You’re feeling fairly vulnerable I suppose, you just want to feel better. The last thing you want to do is start kicking and screaming”.

Anthony; 38; Hospital: 2nd interview.

Maureen, a former Division 1 nurse, said of Ken’s extended hospital stay and her decision not to lodge a complaint at the time:-

“I didn’t take it any further at the time. I just had so much on my plate and by the time that I thought that I’d do something I thought I can’t be bothered. I just want to shut the door and move on. I think probably deep down underneath perhaps I thought Ken’s still here (alive) and they (hospital) might take it out on him and don’t say that people don’t get that in hospitals because I do know and they can and not in a way that you pick up.”

Maureen; 63; wife of Ken; Hospital: 2nd interview

Anthony also commented no-one had made him aware that he had any “rights” apropos the AE. Lack of knowledge about what to do, and indeed the question as to whether making a complaint would make any difference for the better was a factor that influenced Lionel.

“I didn’t know what steps to take at that time. I’d thought about it. It had been in the back of my mind, but I thought why chase them up am I wasting my time? So by the time I mulled it over for a bit, it went out of my mind and move on to
something else.”

Lionel; 68; Hospital: 2nd interview.

The Hospital participants were unaware of the existence of the Office of the Health Services Commissioner (HSC) before our second interview. At their request, I subsequently sent Lionel and Pam contact details and information downloaded from the HSC website.

There was no need for action on the part of Mark and Bruce who received spontaneous explanations about their AEs from remorseful doctors. Roger, Justin, and Mary could not be contacted for a second interview. Whilst I seriously doubt that they sought to take action, I cannot confirm that as fact. Elsie and Carol died in the intervening period. In brief telephone conversations with Don and Jan, both declined a follow up interview saying that talking about the AE was too upsetting. It seems reasonable to conclude, on that basis, that neither had taken action in respect of the AE. Sam confirmed his satisfaction with his care in both interviews.

**Action**

Jane was the only Hospital participant who sought advice, and through a solicitor, being unaware of HSC, paid $4000.00 to have her medical files retrieved and assessed. Jane was advised that she had a good legal case, but after correspondence between her solicitor and the Hospital (under whose insurance policy the doctor concerned was protected), she understood that thousands of dollars were at stake if she proceeded with legal action against the Hospital, and lost.

“And I think they knew that I couldn’t afford to do it so they had me over a barrel. I mean let’s face it: they’ve got their big top lawyers and all that and who am I? The person who’s on a disability thing. That’s nothing to them.”

Jane accepted a modest settlement of $1000.00 from the Hospital, which did not cover her legal fees, nor lost income from her time off work. Jane understood her AE experience and follow-up action as an attempt to bring the doctor to account,
“to kick her ass, and I hope she learned”:-

“if she’s learned something and doesn’t do the same to someone else, well then something good would have come out of it (the AE)”.

Jane; 48; Hospital: 2\textsuperscript{nd} interview.

**HSC and VMIA Participants**

A powerful motivating force lying behind the actions taken by HSC and VMIA participants was the desire to force an acknowledgement of error on the part of the doctor concerned. Angry and frustrated when this was not forthcoming, participants sought out information about potential courses of action in discussion with family and friends (Ros, Wendy, Anna, Christine, Cathy, Margaret, Michael) or their GP (James, Jillian). Participants tried to make sense of their AE by taking action, in order to draw attention to the fact of their AE, in the hope that the doctor would be brought to account bringing about changes in practice and hospital systems such that other patients could be spared the suffering that they had endured. The HSC and VMIA participants are the active patients according to the Parsons model (Parsons, 1951). The participants in both groups had a sense of personal agency that enabled them to seek to find answers about their AEs as well as a form of redress.

Participant Len’s wife Pat was the driving force behind their decision to complain to HSC and said:-

“I’m trying to stop other people going through the hell we went through. I was thinking of other people.”

Pat wife of Len; late 60s; HSC: 1\textsuperscript{st} interview.

Jennifer, Ros and Margaret, the latter two choosing legal action, used almost identical language to describe their motivations:-

“My motivation in all of that was to make sure that what happened to me didn’t happen to anyone else really. I didn’t want it to go unnoticed and unresolved. I
want to make sure that someone else doesn’t go through that type of thing.”

Jennifer; 57; HSC: 2nd interview.

“My motive was (that) I don’t want this to happen to anybody else and somebody’s got to make these people (doctors and hospitals) listen. I just wanted the system to change so that nobody else would go through it (AE).”

Ros; 60; VMIA: 1st interview.

I’m happy if this does actually change something for other women and patients. Generally what I’m about is improving things for myself and the next person. I’m not afraid to take things on. I’ll fight but only if I think it’s a worthwhile cause for everybody, not just for me personally.”

Margaret; 40; VMIA: 1st interview.

Brian and Michael also cited a desire for acknowledgement of the mistake as the motivation behind their respective courses of action. By exposing the AE, they hoped that there would be “learning” from it and processes put in place to prevent it happening to someone else.

Doctors who were dismissive of participant concerns or failed to acknowledge them entirely fuelled their resolve. For a number of participants, making a complaint constituted a validation of the harm suffered. Janet in the first instance had gone to HSC. She was “disgusted” by the doctor’s response to her 6 weeks after the operation when she was concerned about the numbness and lack of mobility in her leg: “he couldn’t have cared less”. By the second interview Janet had successfully taken legal action. Initially she had ruled this out because of cost, but as her mobility declined, she foresaw that she needed some compensation by way of provision for extra care needs as she aged. After all, she reasoned she had gone into the operating theatre in good faith and never imagined she would suffer an AE. Taking action was the “right thing for me to do, for my own peace of mind.”

“I didn’t want to sue just for the sake of suing. He was just so blasé about the whole thing. It was ‘oh never mind, it’s happened to you. Forget about it.’ I thought, no damn him. He’s made the mistake. He’s buggered up my leg completely. Why should he just walk away and say ‘it’s not my problem’? I think
that’s probably what decided me mainly to go through with the Court hearing.”

Janet; 60; HSC: 2nd interview.

Similarly, Carolyn was also strongly motivated by the lack of concern shown by the surgeon who failed to respond to requests by other practitioners to attend to her post-operatively when she started and continued to bleed:-

“I think he’s just not a nice person. He’s not an honest person because he should have just admitted it (a mistake) and then I would never have pursued it. He made me want to pursue it just so that he gets into trouble. I really really want him to have to admit that he made a mistake. Why should he get away with it? I haven’t heard from him. I know 3 doctors paged him and he just didn’t return any calls. Just had this ‘why should I’ attitude. I thought he got paid. He should give back the money.”

Carolyn; 30; HSC: 1st interview.

Papers that Carolyn obtained under the Freedom of Information Act contained a copy of a handwritten facsimile sent by the surgeon to the hospital where the procedure was performed. He asserted, inter alia, that as a public patient she had no right to regard him as her personal physician. Unsurprisingly, even after a successful legal action, Carolyn’s anger and indignation towards the surgeon was unabated:-

“The fact that he was happy to let me rot in hospital that whole week. Obviously he wasn’t going to care if I died or not. He wasn’t going to come and check. I guess I have got angrier as time has gone by and to this day I still can’t believe that I never laid eyes on him.”

Carolyn; 30; HSC: 2nd interview.

Christine did not want to go to Court, rather she wanted the doctor with whom she had had a longstanding relationship to admit that he had made a mistake and to acknowledge the impact of that on her:-
“I just wanted Dr S to know that what he did was wrong. If he acknowledged that and came and said to me ‘look I’m sorry because I should have paid some attention to you when you kept coming back to me every month, every 2 weeks, saying you were sick’ that would have been enough for me because I really liked him as a doctor”

Christine; 50; VMIA: 1st interview.

Acknowledgement of error and of himself as a person who had suffered as a result was at the heart of Brian’s HSC complaint and subsequent exploration of legal action:

“If I had heard the ‘whoops’ and ‘sorry’ I think I would have been very empathetic to that. I make enough mistakes during the day myself to understand that happens. It would have changed my behaviour and my feelings about all this (AE). It would have changed where it went, insofar as a complaint to HSC and maybe litigation”.

Brian; 41; HSC: 1st interview

Practical considerations also came into play with a number of participants explicitly stating that they wanted compensation in order to recover expenses they had incurred as a result of the AE (Doris, Margaret); to make provision for the assumed extra care they would require as they aged (Janet); and for their pain and suffering (James, Michael, Ros, Len).

**Summary of Chapter**

This is the first of 4 Chapters documenting my research findings. I have sought to inform the reader about the breadth and complexity that an AE introduced into the lives of participants and their families. I have outlined the patient journey taken over time following an AE. I have deliberately used extensive first person quotes to give voice to participants in a way that they struggled to achieve in their doctor/hospital experience. The impact of an AE transcends the merely physical, damaging though that may be, and touched the psychological core of many participants. The fundamental expectation was that as patients they could trust in
the care provided either by the doctor that they knew beforehand, the one that they had never met before but on duty at the time and in the public hospital system generally. Participants have spoken on their own behalf in this Chapter, as they will in the next, when they reflect on the significance of, and their learning from their AE.
Chapter 7:
Participant Reflections on their AE Experience.

Introduction

In the previous Chapter, I documented the impact of an AE on an individual and his or her family, and examined how participants responded to often life changing events. In this Chapter, I look at the way an AE shattered assumptions and changed participants’ world view. The faith and trust that participants had had in doctors and the medical system now seemed misplaced, requiring a change in attitude, lowered expectations, and proactive management of one’s future health care needs. Everyone had a different story to tell after their AE. Participants who followed a complaint or legal route often experienced the equivalent of a second AE as their expectations as to what the process would deliver and the perceived outcomes differed markedly. With few exceptions, participants’ emerged from the AE and its aftermath damaged, disillusioned, world weary: it was a journey they had not bargained for when they signed up for medical care in hospital.

Reflections on the Doctor/Patient Relationship: A Loss of Trust

Participants were damaged by an AE in many ways and the lessons learned from it were hard ones. In Chapter 4, I referred to the work of Charles Vincent and his findings about the impact of an AE on an individual, emotions ranging from loss of trust and fear and anxiety about future treatment (Vincent, 2003). Faith and trust are words that keep recurring in patient stories describing the hope and expectations associated with their medical and hospital care. These words offer a context for the disillusionment that typically flowed from an AE. All participants began in a trusting way but that imploded with an AE. Giddens provides an explanation in the sense of ontological insecurity that kicks in when taken for
granted assumptions, in this case about the quality and safety of medical care, are found to be misplaced when an AE occurs (Giddens, 1991,p.36). The participants and doctors were not at any stage on a level playing field. Hugo, Christine and James identified the power imbalance in the doctor and patient relationship and their sense of powerlessness or paralysis. I begin with Hugo, who had an eardrum punctured during routine temperature taking. He had no experience of doctors or hospitals until a work related accident resulted in a hospital admission.

Hugo found himself in unfamiliar territory, without a guide or terms of reference as to how to negotiate his way through a complex system. In retrospect, Hugo thought he should have been “smarter “in his dealings with doctors, which was both a self- deprecating comment and an aspiration. When Hugo outlined his limitations when dealing with doctors, he encapsulated the experience of many hospital patients.

“I haven’t really had that much education and plus I didn’t really have that much to do with doctors in the past. I probably expected a lot more from them than what they actually give. Because I put a lot of trust in them and I just sort of felt a bit let down because I should have been much smarter when I was dealing with these people. But because I haven’t had much experience with doctors in the past I put a lot of trust in them. I think I expected a lot more from them than what they actually gave.”

Hugo; 37; HSC: 1st interview.

Christine berated herself for trusting too much. She took on a portion of blame for her AE saying that with the benefit of hindsight she should have done some research about her symptoms and proposed medical treatment. However, she had emotionally invested in, and trusted, the 20 year relationship with her doctor, deferring to his advice, despite a lived experience of pain and discomfort. Christine adjusted her expectation of doctors, sadly reflecting that notwithstanding a long prior relationship, she felt relegated to the status of a number rather than a patient, or a person, and the doctor that she thought she knew might not have time to listen to her concerns properly.
“My fault was that I put all my faith and trust into that one doctor. He’s a specialist, you’ve known him for 20 years and you think he knows what he is talking about. I’m just a normal patient. I’ve got no experience (and) because of that you don’t question him. What I should have done is gone to another specialist or done my own research. You should never ever put that trust in one doctor. Even if you know them for so many years because they could be having a bad day. Maybe they’re not listening to what you are saying because they’re in a rush. You really can’t put any more trust in them. You don’t know whether you’re a number or a patient. They think of you as a number and that’s very sad to think.”

Christine; 50; VMIA: 2nd interview.

James had done his homework and consulted a neurosurgeon, on referral, one with senior standing and impressive qualifications. James trusted him completely and consulted him repeatedly over an 18-month period, even though several treatment plans failed to resolve his symptoms. The shock of learning that he had suffered an AE, at the hands of his chosen doctor and after repeated consultations with him, and an AE only revealed after emergency procedures, shook James and his family to the core. James and his wife Judy understood the AE as a preventable act and one of medical negligence. James’s surgeon said the “sorry” word in a one on one consultation with James after the AE, in an appointment at James’s instigation. James did not hear ‘sorry” as a genuine apology, rather he understood it as part of a process, a process that potentially would deter him from taking legal action. James retrieved his files from the doctor. He and his family were never going to trust doctors again.

“If you’ve lost your trust: we have lost trust. Especially with someone of so high a rank, and such capabilities and so many initials after their name. You would think they would do the job to the best of their ability, whereas in this case he never did and still does not care. It’s more the element of trust has gone now in the medical profession, except for the local doctor (GP) whom we’ve known for so long. You just lose all faith in someone (into whose hands) you put your life in.”
James; 52; VMIA: 1st interview.

The AE soured James’ view of the entire medical profession, with the exception of his GP, who have never let him down over a 20-year relationship. James’ GP recommended a law firm, saying that whilst his condition could not be reversed, he would have the satisfaction of seeing the surgeon brought to account and in so doing ensure that other people didn’t suffer at his hands. Michael had also assumed that surgeons were “thorough, they’re the best” but after his AE said his skepticism about the professionalism of doctors was such that they would never regain his trust: it was “too deep”. He never intended to consult a doctor again. Margaret shared the aversion to doctors saying that she and her family” only go the doctor now if we’re dying”.

Participants Anna, Jennifer, Janet and Bruce decided that a new strategy was called for when dealing with doctors. Lessons had been learned as a result of the AE: no longer would they defer to the doctor’s opinion. They were going to ask questions of the doctor, and drill down forensically to the last detail of any proposed treatment plan. They intended to seek a second opinion as a matter of course. In other words, following their AE experience, they were never again going to trust the doctor to get their health care right: they were going to be, at a minimum, equal partners, if not in charge. There was a sense of empowerment for some HSC participants, through claiming agency, and accepting some personal responsibility for their health outcomes.

Brian described his new reality with the observation that “I grew up in the Ben Casey era and now I’m living in the House era”. This was a reference to 2 American television programmes. The first screened in the 1960s and featured a nurturing doctor who always found the right answer and treatment for his patients: it was the ‘doctor knows best’ model of patient care. ‘House’ on the other hand has screened in recent years and is a series about a doctor that misdiagnoses illnesses until the very end of the episode when it all comes right for the patient, a disastrous outcome narrowly averted. Brian was no longer of the view that he could trust that it would all come right and whilst wistful about the Ben Casey era when life seemed simpler, “we all long to return to mother’s bosom”, concluded
that time had well and truly passed. Indeed, upon reflection, he was embarrassed, and felt “very naïve and stupid” for having placed “too much faith and confidence” in a person (doctor) that proved to be unjustified. Brain was “ashamed” that through his perceived naiveté he had suffered a hearing loss. The AE was a life changing experience for Brian. It caused him to adjust his perspective and change his approach to the management of his own health care and that of his family. Brian was not going to allow another AE to occur. Future doctor/patient encounters would be different:

“So it’s ceased being a relationship based on faith and trust (with a doctor). It’s now a commercial relationship that I would have with any other service provider. It’s fundamentally changed my view of the medical profession. A paradigm shift clearly: not that I’m a bitter and twisted man at all but it was a bit of a wakeup call. I’d been sold a bill of goods that was based on my cultural upbringing and everything else that this profession (doctors) should be treated in a certain way and through my own experience I formed a quite different view.”

Brian; 42; HSC: 2nd interview.

Brian’s AE redefined his world view in the way Giddens described in Chapter 4. Brian was no longer trusting. His original sense of ontological security, which he now describes as naïve, and feels somewhat ashamed about, has been replaced by a hard-edged business approach, which he will take with him into future medical encounters and he will teach his daughters to do the same. Brian discontinued the HSC process, and abandoned the legal process he undertook because of the financial downside of losing. He felt on the back foot all the time. He had come to the negotiating table openly, wanting a discussion with the doctor, but emerged clear eyed because the process(es) were not going to deliver that for him.

**Reflections on Complaint and Legal Processes: a second AE for many participants**

This is a new section of research, other studies of AEs have not, to my knowledge,
spent time, 3 plus years with participants exploring with them their satisfaction, or otherwise, with the formal processes they undertook following an AE. I did so because at the time I started my research there was considerable debate about legal actions and compensatory payouts in particular. As a trained lawyer, a Master of Laws, I have long held the view that legal processes are not designed to provide outcomes for ordinary people facing the challenges of ordinary life. An AE requires a resolution between 2 people, being the doctor concerned and the patient. The formal processes help some patients, but many participants emerged drained of energy and hope, and cynical. Giddens theory of ontological insecurity seemed very present in the participants as they attempted to negotiate their way through legal and formal processes, with which they were not familiar, and the doctor was the perceived adversary. Participants clearly learnt lessons about their next medical encounter, if there was going to be one, through these various processes.

In the preceding Chapter, participants described their motivations for lodging a formal complaint or taking legal action in terms of holding the doctor to account and bringing about change so that other patients didn’t suffer an AE. This accords with Vincent’s assessment that the decision to take legal action came at least in part from a strong desire to get the doctor and the hospital to pay attention to their plight so that a medical error did not occur for another innocent patient (ABC Radio National, The Health Report, Broadcast 15 July 2002). The expectation was one of acknowledgement of himself or herself as a person who had suffered harm during medical treatment, reporting it by way of validation of their concerns and assuming that there would be improvements made, hospital systems changed, and dodgy doctors exposed. None of this occurred to the satisfaction of HSC and VMIA participants through either process. If participants at the time of lodging a complaint had an expectation that there would be consequences for the doctor, they were to be disappointed. There was a mismatch between participant expectations and perceived outcomes because although hoped for, formal processes did not deliver acknowledgement of error in a personal way for participants. Participants, who had never before been in the position of lodging a formal complaint against a doctor, or a hospital, let alone taking legal action against one or both, found themselves again at a disadvantage, lacking skills and
experience, not dissimilar to their experience of being a patient. They were out of their depth and had to trust HSC officers, or legal advisors. This was the second occasion experienced by participants when those in perceived authority did not hear, nor necessarily care, about their concerns. It was a process; they were in a process; and there were rules and a format to the process outside their control. Participants may have underestimated the degree of resilience required of them by complaint or legal processes, demanding at every turn a response to questions accompanied by requests for further information in order to prove their case before a third party. It was never going to be an easy journey for the average person, and opened up another new and disillusioning world for participants.

The Office of the Health Services Commissioner, which was set up as a conciliatory and mediation body, was a first step for participants who wanted to start an inquiry into their AE and lodge a complaint about their care. None of the Hospital participants knew of the existence of the HSC either when they were in hospital or when I interviewed them 3 years later. Jane, Pam and Anthony commented that information about HSC had not been available to them at the time, and it was only me mentioning it during our second interviews that they became aware of its existence. It was not necessarily of consequence however because only one of twelve HSC participants noted the involvement of the agency as having made a positive contribution or difference (Wilma) to their AE outcomes. Seven out of the twelve HSC complainants consulted lawyers. At the time of my first interview, one of the participants (Vic) had already sued and settled. Germaine was about to issue proceedings but as she did not respond to my request for a second interview, the outcome of that is unknown. She had indicated however that she didn’t trust HSC because it was a government agency and “they”, meaning HSC, and the hospital, were “all in it together”.

In Wilma’s case, HSC was her big buddy, offering a letterhead, and a formal request to the Hospital to honour the undertaking that had been given to meet the cost of building up her shoes after her AE. The HSC had an authority vis-à-vis the hospital and the surgeon, which Wilma felt she lacked on a personal and patient basis. The HSC was a good first step, and the process worked. Wilma got her shoe build ups free of cost. Notwithstanding the advice of family, Wilma did not
want to engage with the legal system and take on the Hospital and the Doctor in order to get compensation. It was altogether too challenging an idea because she had had bad experiences with a lawyer in the past and did not want to revisit the memory. The HSC process seemed manageable, within her reach, and gave her a way forward. Wilma became more confident in her dealings with the Hospital because of the support of HSC:-

“You just feel helpless in a system (hospital) that ignores you. If you try and wave and shout you get hammered down again. And I think they probably would have ignored me had I not gone to the HSC. And how many people would know to do that?”

Wilma; 67; HSC: 1st interview.

The HSC initial response to Jennifer was lukewarm. It was only after the intervention by her second surgeon with photos taken, a before and after visual snapshot, and sent to HSC under his imprimatur, that she felt HSC stepped up and took notice of her complaint.

“It was really only that my other plastic surgeon wrote to them that carried any weight. I didn’t feel anything really happened until he sent photos of how I looked and a letter with it. Then they (HSC) came back to me and said ‘well this is pretty bad’.”

Jennifer; 57; HSC: 2nd interview.

Jennifer received a modest compensation payment of $5000 through HSC, which covered a fraction of her out-of-pocket medical expenses arising from the AE, and on the basis that she didn’t take the matter to Court. Jennifer had never used lawyers before, and the thought of legal action made her feel insecure, and frightened about taking the “extra step”. Jennifer viewed a potential legal process as a “gamble”:-

“I didn’t feel there was anything concrete that I could go on that made it sure that I was the person in the right, even though I was the one who had been harmed by it all (AE). The thing that made me angry was that he was still doing that sort of
thing (making mistakes). And he’s actually trained someone else and (name of her second surgeon) is still getting botched jobs coming to him from that area. For me, it (HSC process) hasn’t solved the problem. This particular doctor has retired but he’s trained someone else in his place.”

Jennifer; 57; HSC: 2nd interview.

The HSC process did not resolve Jennifer’s overall AE concerns because the doctor responsible continued to practice in the area and had trained up a successor, presumably with the same flawed technique. Nothing had changed so far she was concerned: Jennifer’s second surgeon told her he continued to receive botched jobs from the other doctor. Jennifer was delighted with the outcome of her second surgery, but nothing had come out of the HSC process per se, in terms of holding the doctor to account.

HSC officers advised complainants Len and Carolyn that they were closing their cases because of difficulty in proving the case, or having no credible case, respectively. Both consulted lawyers on a “no win, no fee” basis and proceeded on a legal path. Len’s legal case had only just begun at the time of our second interview, and the outcome is unknown. Len’s wife Pat complained about the period of 8 months “keeping me holding” whilst HSC determined whether there was a case, and then told them no, there was not.

Carolyn had written letters of complaint to the Hospital, and the Medical Practitioners Board, without receiving satisfactory responses. Carolyn had kept a detailed documentary history of her AE and she contacted HSC as the next step along the way. Carolyn was outraged when she received advice from HSC that there was no case in their view. Carolyn went on to be a successful litigant. Carolyn described the HSC as “hopeless”:-

“I thought I was doing the right thing and that I was going down the right path (but he said) it was just a waste of time. I was really crapped when that guy rang me and he said ‘I’m on no-one’s side but you have no case whatsoever, and to be told to go away because you’re wasting everyone’s time. He pretty much told me that I would have ended up with a sore throat, no matter what. It had nothing to do
with the surgery. So that ticked me off even more.”

Carolyn; 30; HSC: 2nd interview.

Without a “no win, no fee” option, made available though a family member at a Christmas gathering, Carolyn would not have taken legal action, because it was outside her life world experience, and family budget. Carolyn did well financially out of the legal process. It was a testing experience, the range of interviews required, questions asked, having to prove herself as a legitimate complainant:

“I would give the money back in a flash if I hadn’t had to have gone through it. It has tainted me forever. When the court case was happening I was in tears with every doctor (requisite expert opinion evidence) . Just thinking about it: I don’t like to think about it. I got upset every single time that they asked me questions.”

Carolyn; 30; HSC: 2nd interview.

Notwithstanding all of this effort, the HSC process followed by a “successful” legal procedure, Carolyn remained deeply unhappy because she saw the doctor advertising for new ENT patients in the local paper every week. The doctor had been completely unaffected by her actions, remained unconcerned about her wellbeing, and Carolyn concluded that other patients were at risk.

“Until the time we moved over here (house move) he was advertising for patients in the local paper. Advertising as an ENT(ear, nose and throat surgeon) for patients. I felt like putting an ad right beside his. (The legal process didn’t satisfy) because he didn’t have to do anything anyway. I don’t know if anything comes out of this so that he actually gets reprimanded. That he’s still getting away with it: that annoys me.”

Carolyn; 30; HSC: 2nd interview.

Brian made very critical comments about the HSC process. He was in the early stages of his dealings with the HSC at our first interview and emerged 12 months later very disenchanted. Although there had been a “cathartic” effect in being
able to give his account of events and to have an independent body validate that his grievances about the doctor, the care received, and his AE were all legitimate concerns, so that from Brian’s sense of himself, “it’s not just me whingeing and bitching”, it all ended there. Brian had experience with Ombudsmen’s process, and regulatory frameworks, as part of his job. He used this frame to consider the HSC performance and found that it had failed him. From his point of view, the perceived consumer body to which he had complained had let him down.

“The process with the HSC was frustrating because it was very time consuming and constantly humiliating and embarrassing for me to go through. It became adversarial from the start. I was made to feel I was being a bit too precious about this (his loss of hearing). I felt as if I was on the back foot defending a claim that I was making.”

Brian; 41; HSC: 2nd interview.

Specifically, the conciliation procedure offered no resolution for Brian but only further aggravation because it failed to compel either the Medical Defence agency acting on behalf of the surgeon, or the surgeon himself, to come to the table, and talk to him, acknowledge an error, which was all he wanted ultimately. Brian took out a writ at a cost of $1500.00 in order to keep his legal options alive, but allowed it to lapse, because he could not afford to go forward, lose, and have costs awarded against him. It was a pragmatic decision and he didn’t have a “no win, no fee” lawyer at hand. Brian’s disappointment can be gauged by the fact that he peppered his second interview with the word “frustrated” no less than 16 times, interspersed with “embarrassed”, “humiliated” and “insulted”. Brian drew the following conclusions from the HSC process, and his aborted legal proceedings:

“It (the HSC process) was quite impotent. I assumed it would have been a little more empowered, not so much as to enforce, but the HSC just dropped it. I’m not sure I even would have bothered going along this path had I known that it was without any sort of substance. I understand the conciliation process and I think that’s a good first step but there’s nothing beyond that. What do you when it’s
quite clear that a party has been wronged? You’re left with going through the court system and again that requires an investment and a risk. When I’m not seeking compensation essentially, just seeking acknowledgement, there’s no upside on that bet. Better to get nothing than to lose everything.”

Brian; 41; HSC: 2nd interview.

Participants who engaged in a legal process were emphatically disappointed and disillusioned by it. It opened up another new and unfamiliar world to participants, one where they felt that they were being carried along in a process that essentially operated outside of their control. Whilst they were theoretically at the centre of the process, they recognized it as a machine, a rather dehumanizing one at that, and they were quite peripheral to its day to day conduct and overall outcomes. Margaret reflected on how disempowering she had found the experience. First time litigant, new to legal process, Margaret began with a sense of mission to help prevent other women suffering her AE during childbirth. She was “fired up” by the first lawyer she consulted, a woman. However when the woman retired from the practice, Margaret’s case was taken over by a man and at that point Margaret’s enthusiasm began to wane. As the legal process “wore on”, Margaret became less and less enamoured:

“But I remember feeling all the way through it (legal process) that this is not the world I operate in. I’m out of my depth here. I’m intelligent enough to understand the language and I get what’s going on, but it’s just not something that I would choose to be part of ordinarily. I’d given my power away I guess, or somebody else had control. I felt that I was too far in it to just go, well that will do: stop. So you have to put your trust in these people (lawyers) and then when it doesn’t meet the expectations that are created and the ideas that were created in the beginning again you feel like you’re stuck between a rock and a hard place. You’re halfway through your case and you’ve had 100 tests (medical etc.) and you’ve spoken to loads of people (verifying case). It’s like a machine you know. You’re taken on a conveyor belt and you go through this process and you’re popped out at the other end.”
Margaret; 40; VMIA: 2\textsuperscript{nd} interview.

Ros, who had never consulted a lawyer before, found herself “all of a sudden in this other world”. She likened it to her hospital experience in the sense of feeling disempowered and unacknowledged, but here there was also the prospect of costs being awarded against her in the order of $30,000 to $40,000. As she said, a “normal person can’t afford to pay those sort of fees” Ros had “no idea” that that was how the legal system worked and she was too “scared” to go to Court.

The financial risk implicit in proceeding to a Court hearing was apparent to all, and the disparity in the resources available to participants, as private citizens, and doctors and their medical indemnity insurers was obvious. Jane, Jennifer and Brian have all previously commented on the disincentive that legal costs provided to legal action. Putting the question of costs to one side, the process of mounting a case required participants to undergo rigorous tests in order to establish the bona fide nature of their claim. Carolyn earlier referred to the toll it took on her. James described its bruising impact on him, including the way he was made to feel as if he were the guilty party:-

“And the tension and the pressure. Just going through the amount of tests that I had to do to prove that I wasn’t trying to pull anything off. There were mental capacity ones, memory ones, psychologists, psychiatrists, independent eye specialists. This went on for months and months and months: all at my time and my expense. It was very stressful because a lot of these interviewers, psychologists or whatever always questioned me: ‘Why are you doing this?’. Pointing the finger at me as if I created this situation. They were trying to make me feel as if he (the surgeon) is the good guy. I’m the bad guy. In actual fact he’d done the wrong thing by me but them being specialists themselves. I feel like it’s a closed circle.”

James; 52; VMIA: 1\textsuperscript{st} interview.

In the above quote, James touches on another reason why participants faced a huge hurdle in mounting a successful legal action: the “closed circle” of medical professionals. Jane had abandoned a proposed legal action because her solicitor had been unable to convince a doctor to testify on her behalf. Christine
complained that she didn’t get any satisfaction from going to lawyers. She had wanted to force her doctor to admit that he had made a mistake, and whilst 2 doctors she consulted were of the view that his surgery had resulted in her AE, they were not prepared to support a legal action:-

“Professor P will tell you off the record but he won’t put it in writing. The other doctor, Doctor B said it to my face who caused all these problems for me but she wouldn’t put it (down) on a piece of paper. So everything is off the record. They talk to you, (give you) their opinions but they’re not going to put it on a piece of paper because they are scared of doctors going against doctors, or they don’t want to be caught in the middle of these legal things”.

Christine; 50; VMIA: 2nd interview.

Margaret spent 3 years seeing “endless” specialists and had three further surgical procedures trying to get herself “fixed”. However, it was only when she consulted lawyers, who in turn sent to her to Melbourne specialists, independent of the doctors in her regional area that she began to have her suspicions about the causes of her condition confirmed. For the first time, a doctor gave her an honest and direct opinion about cause and effect, a discussion that her local doctors, including her GP, had avoided. When it came to the question of giving expert evidence in Court, the potential expert was again missing in action:-

“They started giving me answers that were more satisfying. There was one doctor that said categorically ‘Yes, this happened (development of an anal fistula) directly as a result of that (anal sphincter muscle cut during episiotomy)’ but when it came to getting him up in court he backed right off and said ‘no, no, I can’t do that’. He wouldn’t be an expert witness, so that’s why I ended up in mediation rather than in the Supreme Court. And that doesn’t inspire confidence in the medical profession. It just seems to me that they’ve all got each other’s best interests at heart (rather than the patient). It’s all in house”.

Margaret; 40; VMIA: 1st interview
Although Anthony did not take any action in regard to his AE, he had given the situation a great deal of thought and applied his own life experience, and reflected on the performance of doctors, accountability as he understood it, and the code of silence that existed between them as he perceived it. There had been two surgeons in the operating theatre when his initial AE occurred, neither of whom had “owned up” to him:

“I mean I don’t know if there’s a code of ethics amongst doctors. I mean they don’t seem to pile too much dirt on each other. I mean from a tradesman’s point of view, if I walk into a house and I see something that’s not right, I have no problem pointing out what’s wrong. There’s an actual code of practice to stop dodgy operators. I see no reason why that shouldn’t be in the medical trade as well. There should be someone keeping an eye on them and making them accountable for any mistakes they do make. They’re pillars of society supposedly and they get paid big bucks and people are in the palm of their hand. They could have a good day or a bad day but if the bad days outnumber the good, they shouldn’t be doing the job.”

Anthony; 41; Hospital: 2nd interview.

The suggestion in Anthony’s comment is that doctors did not seem to suffer any consequences for poor performance and he puzzled about how that could be.

Anthony’s observation was shared by other participants, and for those who had subjected themselves to a gruelling process, it was a particularly galling realisation. Christine’s purpose in taking legal action was to force the hand of her doctor and get him to acknowledge the harm he had caused her. She expected, at a minimum, that the doctor would be questioned so that he could learn and not repeat his mistake. In her view, the “whole system” should be examined, and/or changed, when a patient suffered an AE and that included hospital procedures. Sadly for Christine “nothing like that happened”. It is in the nature of out-of-Court settlements that the process takes place between lawyers for the plaintiff on the one hand and lawyers for the doctor’s medical indemnity insurers on the other.
Statements of claim are submitted and then negotiated between the lawyers until a settlement is reached. This explains in part Margaret’s previously reported comment about how superfluous she felt to the process. Over the course of 2 years, Ros had 3 meetings with her lawyers. The third meeting was “settlement day”. From Ros’ perspective the entire legal process had been a waste of time because she had not had an opportunity to put her case directly, to speak with the doctor, or with the hospital’s representatives. At the outset, Ros wanted an acknowledgement from the doctor that he had made a mistake and that he treated her children in a high handed and dismissive manner. She thought she would be able to say what she wanted. Instead, the case came down to one of medical negligence and proof. There was no room for her to express her emotions: it was all cut and dried in a legal sense. Ros signed a confidentiality agreement, in return for which she received a payment. She regarded this as “hush money”: she had been paid in order to get out of the way, and keep quiet about the circumstances of her AE. The legal process was an extension of her hospital experience: Ros had not been heard. It had been a meaningless exercise.

James also had an expectation that the legal process would allow him to “eyeball” the doctor and have a ‘you did it’ conversation”. He had been encouraged in that view by his GP. Perversely, the fact that the doctor admitted his liability to the medical indemnity insurer robbed James of his day in court which is what his wife Judy said he really wanted. By signing the confidentiality agreement James was prevented from speaking out and exposing the doctor. James’s injuries were very serious, loss of sight in one eye, sight in the other poor, sense of balance disturbed. James was afraid that he could be out of a job at the age of 52 because he could no longer perform to the best of his ability as a plumber because his skill range had been greatly reduced. The AE had turned James’ life on its head, yet the doctor responsible continued to practice, and could through lack of care potentially wreak havoc in someone else’s life. James, knowing all of this, could not do anything about it. The outrage of it all, struck James and his wife very personally when Judy visited her sick uncle in hospital, only to find that James surgeon was the treating doctor. Judy turned on her heels and walked out of the room, after having introduced herself to the surgeon by her
married name, and as James’ wife. Judy’s recollection was that the surgeon’s “jaw dropped”. Judy had observed the protocols of the confidentiality agreement. The added cost of the AE to James and Judy was in not being able to warn someone they loved about the risks posed by a particular surgeon. They, James and Judy, kept their part of the contract leaving James an angry and frustrated man, a muffled voice, choking with the unfairness of the situation:

“He has the power to be able to have representation (and) not to be concerned about it. He just pushes it to one side (and) lets his legal team do everything. But the worst part is though he’s still doing this now: right at this very minute. He’s still operating and you know carrying on his profession. The people that he is treating don’t know that he is capable of such a lack of duty of care. He’s a big fish in the market and he can get away with it. He gets no repercussions because no-one knows about it. No-one can openly bring out that this man is not held accountable for his actions. And he’s just going on willy nilly about his business. His life hasn’t been affected. Yet he can still affect someone else. And the system allows him to do it. He hasn’t been held accountable”

James; 52; VMIA; 1st interview.

The “system” had let James and his family down. Legal process had not equated to justice in a moral sense. The VMIA participants, and Carolyn and Jennifer from HSC, had received compensation payments yet none felt “compensated”. Theoretically they had “succeeded”, yet none were happy with the process or the outcome. Even the two VMIA participants who did not have ongoing health issues remained dissatisfied (Doris, Michael). In both cases they were frustrated that nothing had been done or implemented, so far as they could see, as a result of their complaint. In Doris’s case, her husband Brendan explained their grievance as:-

“In the absence of the hospital saying’ look we’re sorry, we goofed’. Then no. I mean we got our money back, but then that’s money we shouldn’t have had to pay out in the first place. I mean we’re hoping that they (the hospital) took notice of what caused it (the AE) (and) tighten things up a bit. But we don’t know that they did. And had they just written a letter saying we’re sorry, we goofed and we
will try not to do that again: it could have been wonderful.”

Brendan; husband of Doris; 73; VMIA: 1st interview.

Michael was none the wiser after his legal action as to how a swab had been left in his abdominal cavity, who was responsible, and what steps had been taken to ensure that another patient did not undergo his “trauma”. It was this thought that still “played” on Michael, the concern that his action had not brought about any positive changes. Michael wondered why he had bothered. Compensation was never an issue because he did not have any ongoing health concerns, or expenses that he needed to recoup. Michael had simply hoped for changes to practice.

**Summary of Chapter**

In this Chapter, I have informed the reader about the fundamental loss of trust in doctors and the medical profession that many participants experienced following an AE. Ontological security, as described by Giddens in Chapter 4, was shattered for many participants by an AE. For many participants, it was unlikely that trust in the medical fraternity or the hospital as an institution, particularly in a site sense, could be regained.

However many participants turned to formal complaint and legal processes as a way of obtaining acknowledgment of error and of harm caused, bringing the doctor to account and getting some recognition for the harm that had been caused to them personally. There was also a hope among many participants that if they took action it would help ensure that other patients would not be harmed by an AE experience in the way that they had been personally. This was a genuine concern and widely expressed amongst participants. I initially dismissed the concern as altruistic, but came to understand it as part and parcel of the AE patient journey expectation, and the way participants could feel that they were making a contribution by bringing about changes in medical and hospital practice that would be of benefit for other patients on the hospital journey. It was also a way of making meaning out of their own AE experience, a desire to make things
better. Talking and complaining can lead to meaningful changes, and who better than those with real life experience of doctors and the hospital system.

However formal processes, neither HSC nor VMIA met the needs of participants, other than on a few occasions, because the doctor concerned was not involved in the proceedings. The doctor was not available. Participants discovered that the act of taking action was difficult, time consuming, costly, and burdensome on them, with the finger pointing at them in terms of establishing a burden of proof. The costs associated with a legal action deterred a number of participants from proceeding with what they considered legitimate claims. Another major difficulty in bringing about a successful legal case was the unwillingness of doctors to appear as expert witnesses, one against another, in court. Participants concluded that the odds were stacked against ordinary citizens such as themselves when confronting a legal system, as well as a medical fraternity that was seen to look after its own, sometimes at the expense of patients. An acknowledgement was what was wanted and compensation for what they had paid out by way of their health care costs to date, and anticipated future needs. An AE had been life changing for participants yet the sad realization for those who had run the gauntlet of complaint and legal processes was that nothing fruitful seemed to come from their effort. Doctors apparently lived in a parallel universe: they had emerged unscathed by the consequences of their AEs. There was considerable doubt and suspicion that changes had not been made to hospital practice and procedures arising from AEs, and therefore further AEs were likely to have occurred. Participants had been catapulted into a different world by their AE. Their efforts to address the situation, however taken, and to make a difference for others, came to naught. The lessons that participants learned, directly and indirectly, from their AE, were bitter ones.

In my next and final findings Chapters, I introduce the 4As as a way of explaining patient responses to an AE and introduce a Model as a way of abstracting responses and applying them more generally.
Chapter 8:

The 4As, a 4A Model,

Pathways to Anger or Resolution.

*Figure 1: Isaiah 49:15-16*
Introduction

In Chapter 6, I documented the complicated and often painful journeys that participants undertook following an AE, explaining the breath and depth of the experience. In Chapter 7, participants reflected on the AE as a life changing experience, and on the actions they took as a result, the reasons why, and the perceived outcomes of those actions.

I introduce this Chapter, with a very moving image: one of tenderness and trust. The Biblical text of Isaiah in Chapter 49 verses 15 and 16 speaks of a woman forgetting her child or showing no compassion for the child of her womb. The intent of the author of the Biblical text was to dramatise for the reader the counter cultural nature of such neglect and/or betrayal, and to emphasise by way of counterpoint a loving and attentive God. The message of the text is one of human fragility and neediness with the thought that God will remember and care for each individual. My purpose in introducing Chapter 8 in this way is to draw an analogy with the doctor/patient relationship in terms of patient expectations when they hand themselves over into care, placing their trust in the one or the ones, the doctors and the hospital system, who will look after them. Doctors, in a literal and metaphorical sense, “hold patients in the palms of their hands”: Anthony; 41; Hospital; 2nd interview. Each patient is a person with their own personal history, particular needs, and expectations of the doctor and patient relationship. Participants across the three groups commented on the lack of concern shown by the doctor(s) about their individual well-being after an AE, and their general unwillingness to accept responsibility for it, at the time, and over time.

In this Chapter, I document the 4 key themes that emerged from my thematic data analysis of patient experiences of AEs. The key themes are acknowledgment, apology, accountability and anger (collectively described as the “4As”). I introduce each section of the 4As with a diagramme which describes the essential elements of each “A” from a patient perspective, followed by a detailed analysis supported by participant quotes. In a set of 3 diagrammes, I mapped participants by group against each of the A points, using a scale of zero to 5 to reflect how strongly they identified with any particular A or As. In a fourth diagramme, I show the combined participant
responses and relative weight attached to each of the As. In the next Section, I
discuss the interrelationships between the 4As and conclude with 2 further
diagrammes showing the alternative Pathways for participants following an AE, one
which leads to anger and the other to resolution. This is a dynamic Model, and the
demonstration of the interrelationships of the 4As, and the inferences to be drawn
from that, are capable of generalization to other contexts and settings beyond the
experience of an AE. I begin with a simple version of the 4As.

*Figure 2: The 4As*
The First ‘A’: Acknowledgement

“I will not forget you…I have held you in the palm of my hand”: Isaiah: 49:15.

The doctor patient relationship embodies the words of Isaiah in the sense of the trust and expectations invested by patients either in a particular doctor or more broadly in doctors working within the hospital system, and in the hospital system more generally. The words “I will not forget you” equate from a patient perspective to an expectation of being remembered, as an individual with particular needs, that require care and attention during hospital stay. When an AE occurs, the doctor concerned exacerbates the suffering of the patient when he or she fails to acknowledge the patient experience of something having gone wrong, and the role that he or she (the doctor) played in the patient outcome. Acknowledgement is the pre-eminent A of my 4As. Apology and accountability are closely related, but distinguishable. “Acknowledgement” requires a personal exchange and engagement, relationship based, between the doctor and patient. The importance of a personal exchange is consistent with the early finding of Charles Vincent who commented on the distress caused to patients, and the long term consequences for patients if an AE was not handled well at the time, by which I mean with sensitivity, openness and respect (Vincent, 2003, pp. 1054). Iedema reported in a retrospective study of an ‘open discourse process’ that patients remained unsatisfied because there wasn’t a personal engagement with the doctor concerned (Iedema, 2011). The need to be listened to, and the harm caused acknowledged, was also reported on by Micalizzi and Bismark in a study of parents’ responses to their child’s AE (Micalizzi and Bismark, 2012).
Figure 3: Acknowledgement

**What Constitutes Acknowledgement**

- **Personal**
  - Mistake mode
  - Apology given
  - Acknowledgement of the patient as a person who has been harmed or had their life impacted, and that the family was “being taken seriously” and being listened to.
  - Assurance that Doctor will do better next time

- **Process**
  - Behavioural change from the Doctor and Hospital “System” change

- Protect others
- The Doctor “Learning” from the AE or experience
A lack of personal acknowledgement by the doctor of the AE, and of the harm caused, informed the responses of the majority of my 33 participants. It was a key issue for James, Ros, Margaret, Brian, Carolyn, Wilma, Jennifer, Janet, Anna, Norma, Hugo, Lionel, Ken, Mary, Carol, and in the second interview included Anthony and Jane. It was the primary motivating force behind participants lodging a complaint or taking legal action. Drawing on their evidence, I concluded that “Acknowledgement” has essential elements in order to be heard and understood by a patient, as a helpful way to negotiate the confusion associated with an AE. From a patient perspective, there are clear expectations of the doctor:-

- Acknowledgement of the patient as a person who has been harmed; listening sensitively to the patients’ concerns or anxieties and taking them “seriously”;
- Acknowledgement, by the doctor to the patient directly, that a medical error has occurred on their watch, for which he/she accepts full responsibility;
- An apology is offered;
- Accountability is accepted.

The lack of acknowledgement by the doctor about Janet’s AE prompted her to take action against him.

“When I went back to see him [surgeon] 6 weeks after the operation, he couldn’t have cared less. That was the real decider for me [lodging complaint]: his attitude. He couldn’t have cared less [about condition of her leg].”

Janet; 60 HSC: 1st interview.

Janet commented in our second interview about the “attitude” of the doctor who “wasn’t really interested after the operation”. Janet understood that the doctor no longer saw her condition as his “problem” and whilst framing this as “I know they [doctors] are busy and they can’t take every case personally”, that is exactly what she wanted, and failed to achieve.

In Jennifer’s case, the doctor denied the reality of her AE experience and prescribed sleeping pills instead. The “problem” was, apparently, all in her mind.
“It made me more resentful towards him: thinking ‘you’re not dealing with the problem at all. You don’t even want to know about the problem. He obviously knew that (something was wrong). I could tell by his attitude because he just wanted to push me out the door. He didn’t want to sit there and discuss it. He was, you know, get me in and out (of his rooms) as quick as he could. So I knew that he knew that there was something wrong”.

Jennifer; 57; HSC: 2nd interview.

Wilma’s surgeon brushed off her concerns about the discrepancy in her leg length post-operatively. When she had first consulted him Wilma assumed that she was in excellent hands because “he told me how brilliant he was”. Afterwards it was a different story:-

“And I kept saying ‘It feels like a lot’ and he kept saying ‘no, no, it’ll settle down’. I think he originally said 6 months and now it’s up to 2 years. I mean his whole attitude was that it wasn’t that much of a problem. I think the closest that he [naming surgeon] got to sort of admitting [that there had been an error] was to say it was ‘unfortunate’”.

Wilma; 67; HSC: 1st interview.

Wilma considered that the doctor had “stuffed up” and it was his “unwillingness to admit that he could have been fallible that was annoying”.

In our first interview, Ros used the word “acknowledgement” several times to describe what she most wanted from the doctor who had caused her AE. She summed up in the second interview:-

“I had no idea about anything really at the start [of her legal process] except I just wanted some acknowledgement that he’d made a mistake and some acknowledgement to my children that he treated them terribly”.

Ros; 60; VMIA: 2nd interview.
Bruce’s focus was on a personal acknowledgement of error and an assurance of change:

“*I was essentially seeking some sort of acknowledgement, that there’s learning and behavioural change that others wouldn’t be put in the same boat*”.

Bruce; 41; HSC: 2\textsuperscript{nd} interview.

**The Second ‘A’: Apology**

The words “I apologize” or “I am sorry” have the capacity to be experienced by a recipient as a powerful tool towards healing when expressed in an open and honest way, one to the other, by the person who has caused harm (Lazare, 2004, p.44).

An apology in the form of an expression of regret was integral to the “Open Disclosure” trial protocol of my initial research. The words have to resonate, and be heard as sincere, and come at some cost to the person offering the apology, in order to make a difference and constitute a meaningful exchange. The importance of a meaningful exchange between the doctor and patient is demonstrated in the following diagramme, where participants enabled me to deconstruct their experiences of good and bad apologies. This differentiation was implicit in Vincent’s finding as to why people sue doctors (Vincent, 1994, pp. 1609), a continuing, relevant analysis. Micalizzi and Bismark (2012), call for a “heart” response, by which they mean a heartfelt response to a parent whose child has suffered an AE. An apology with no consequences for the giver, does not have the requisite and desired sense of accountability for the person receiving it (Berlinger, 2005, p.60).
The meaning of an apology is lost when words are used in a shallow or formulaic way, with an expectation that simply by uttering them, that all will be made well, all things forgiven, and relationship restored. In the context of a doctor and patient relationship, an apology has to be personal. Participants differentiated between “good” and “bad” apologies, as demonstrated in the preceding diagramme. A good apology required:

- an acknowledgement of the patient, as a person, who has been harmed and whose life has been impacted either temporarily or permanently as a result of an AE, by the doctor concerned;
- personal ownership of the error by the doctor and the provision by him/her of a full explanation;
- a heartfelt sorry, that is, one which the patient hears as genuine, thereby providing an opportunity for the patient to choose to forgive the doctor and the incident.

A good apology is not about what is said, or how it is said, but rather by whom it is offered, and in what spirit: a genuine person to person exchange, with one accepting responsibility for events that caused harm to the other, albeit unwillingly, is essential. A genuine apology is restorative to the recipient, “heals a wound”, and restores a sense of dignity (Lazare, 2004, pp. 242) This is particularly apposite for patients who have suffered an AE: their expectation was a trusting one, of another, in a position of power, and hope from their perspective of a formulaic apology was of little comfort to participants.

Only 2 of my 33 participants received what could be regarded as a “good” apology, by which I measure participant response to an acknowledgement of themselves as patients who had been harmed unwittingly, an admission that a medical error had occurred, and that as a result further and unexpected surgery was required. In both cases, the doctor responsible stood by the patient’s bedside in order to discuss the situation, one on one. I discuss these participants later in this Chapter. First, I will discuss all the participants who received something other than a good apology. This happened in various ways.

Expression of Regret in Open Disclosure
Six Hospital participants received an OD protocol following a discerned AE according to Study protocols. This constituted a full and factual account of the AE and an expression of regret, as distinct from an apology, by a senior clinician who had not been involved in their care. At the time of my first interview with Hospital participants, their response to an OD had been minimal. Some participants had been too ill or distracted by their own physical conditions to pay attention to or absorb the OD intervention information. For others, it mattered little at the time, either in not taking them forward in their understanding of their condition (Sam), or not particularly caring about it (Justin). Anthony however was keeping a watchful eye on Dr P with whom he had consulted prior to hospital admission, and of whom he had personal expectations. The OD did not tell him anything new. Dr P. had informed him of the risks of surgery, and Anthony had accepted them. Dr P had informed Anthony of the AE, without further explanation, of which more later. An OD does not equate to an apology however because it did not involve a personal engagement between the doctor responsible for the AE and the patient who has been harmed. For these 6 participants, the OD was delivered by a senior mentor of the medical staff, but not the treating doctor. This was in accord with the protocols set down by the Human Research and Ethics Committee of the site Hospital. There was no formal, state of Commonwealth protocols in place at the time of the Hospital based part of my study around OD, but the Lexington Model referred to in Chapter 5 was under discussion, and VMIA underwrote the initial study on that basis. The Australian OD Framework that was subsequently adopted (Australian Council on Safety and Quality in Health Care, 2013) reflected the approach taken in the study. An apology constitutes an expression of sorrow and sympathy, the use of the words ‘I am sorry’ or ‘we are sorry’ is recommended. The Open Disclosure Framework gives doctors, the ones who have caused an AE, the option to participate in an OD, if they feel prepared to do so.

**No Apology**

Twenty two participants did not receive an apology (including the Hospital participants referred to above). Participants from the HSC and VMIA groups would have welcomed an acknowledgement by the doctor of their perceived suffering following an AE. Brian, Christine and Carolyn said that they would not have taken action if they had received an apology; an acknowledgement of
error, from the doctor that they considered was looking after them. Brian, Christine and Carolyn said that they would not have taken action if the response from the doctor had been different from the one experienced.

“If I had heard a ‘whoops’ and ‘sorry’, I think I would have been very empathetic to that. I make enough mistakes during the day myself to understand that it [mistakes] happen. It certainly would have changed my behaviour and my feelings about all this. It would have changed where it went insofar as a complaint to the HSC. I kind of visualise that if I had had that ‘whoops’ and ‘sorry’ and an explanation [as to what had happened] I would have understood ‘well shit happens’“.

Brian; 41; HSC: 1\textsuperscript{st} interview.

I really liked [name of doctor] before but when I go through the pain every day I wish he felt that pain himself. If he came when he found out I was so sick in hospital: he should have just rung me and said ‘I’m sorry I ignored you [dismissing her concerns] for 6 months’. If he had said those words, I would never have done anything [taken action]. That would have been enough for me. I mean I didn’t want to sue anybody.

All I wanted was for the doctor [her original treating doctor] to say that he was sorry for what he had done [failing to listen to her concerns]. I understand that we all make mistakes.”

Christine; 50; VMIA: 1\textsuperscript{st} interview.

Carolyn first lodged a complaint and then went on to sue successfully. She reflected:

“I think it settled at $70,000 odd [her Court case] but it would have been nicer for him to say sorry in the beginning. I didn’t want anything out of it at all the way along except for him to apologise and whatever. In the beginning that [receiving an apology] was the only thing. The thought never crossed my mind to sue.”

Carolyn; 30; HSC: 2\textsuperscript{nd} interview.
Rejected Apologies

Jane, Norma and James rejected the apology offered because it was not heard as being sincere and heartfelt, rather formulaic and process driven. The doctor failed in each case to admit that he/she had made an error that had caused the participant harm. “Just saying sorry” was not good enough. Taking personal responsibility for an error is essential, the raison d’etre of giving an apology. Where the person responsible does not acknowledge the harm, and accept responsibility, the apology is perceived as having little or no merit by the recipient (Lazare, 2004, pp. 74). Simply using the “sorry” word will not be sufficient to convince the recipients of genuine remorse and by doing so may exacerbate the recipients’ angry feelings, because it is felt and heard as insulting and demeaning (Lazare, 2004, pp.99)

Mazor found that more than words are required when treatment for cancer patients went awry, and that evidence of improvement in practice was an important, but missing, component (Mazor, 2013, pp. 341)

“Well that lady doctor, the one that was so smart about everything: she actually apologised to me. I didn’t like her. I thought she was just a smart thing. Everything was a big joke. I mean she didn’t say to me ‘I made a mistake’. Put it this way it didn’t convince me that she was really sorry.”

Jane; 48; Hospital: 2nd interview.

Norma was the only one of the twelve HSC participants who received an apology and she rejected it because the doctor failed to take personal responsibility.

“The thing that really upset me was him trying to shift responsibility, not admitting his part in it [AE]. Perhaps he thought saying sorry was enough. But just saying that it [AE] was caused by equipment failure was not enough. Dealing with all these highly educated men and for them to say that it was just equipment failure is really pathetic He wasn’t prepared to ask what was his part in all this”.

Norma; 56; HSC: 1st interview.
James was the only one of the six VMIA participants to receive an “apology” and he found it inadequate:

“And he sat back down with this smug look on his face and he said ‘I’m sorry’. He said that ‘I can assure you that it won’t happen to anyone else. I am one of the highly regarded neurologists here.’ He never once said that he made a mistake: he just said that he was sorry. It was if to say, ‘well tough titties, stiff shit: it’s happened to you’. That’s the impression I got and I was that close to losing it emotionally. I just said ‘well you’re sorry. You’re not going to do it to anyone else. That’s not good enough. I trusted you completely’.

James; 52; VMIA: 1st interview.

The Longed for but Missing Apology

Hospital participant Anthony, three years into 2 sequential AEs, expressed what an acknowledgement by the doctor and an apology would have meant to him. During our second interview, Anthony used the words “sorry” and “apology” 19 times.

Anthony’s account of wanting an apology illustrates graphically the importance of an acknowledgement and apology by his trusted treating surgeon in the AE experience and his subsequent psychological healing.

“I mean I’d be more than happy with just an apology [for] sort of stuffing me around. I can’t think of anything else that would satisfy except just getting it all fixed – you know sort of dusting you down and putting you back as you were when you first came into the place. Then you’ve got somebody to forgive too. Someone’s apologised [for what’s happened] and you forgive them. I mean that means a lot to me. ‘Sorry I stuffed up [but] I won’t do it again’. Then you say ‘Yes well that’s alright. Just make sure that you don’t do it again’. That would put it to bed basically. The apology would be nice. [It] would be a human touch. I mean you go in there [hospital] being human and you’d like to think that they’re human too. And again it puts the shoe on the other foot. I mean it’s up to me to accept the apology and that’s only if I think it’s a heartfelt thing. I mean I wouldn’t accept a ‘Well I’m sorry’. It has got to be filled with meaning. I don’t mind being a
forgiving guy as long as I get to forgive the person who admits that he buggered up. I have brought the kids up to be like that so it’s something that I expect out of other people. It’s just the right thing to do. Not so much that you want retribution but you want acknowledgement. You want them just to say sorry: ‘I’ll never do it again. I’ll be more careful next time’. If not for me then for the next person they operate on. It would be reassuring and you’d get a sense of well you’ve done the right thing by making him apologise”.

Anthony; 41; Hospital: 2nd interview.

The Third ‘A’: Accountability

Following an AE, participants expected the doctor to acknowledge directly that an error had occurred, albeit unwittingly, and that he/she took responsibility. When there was no admission of error, or participants felt that the doctor was avoiding the issue, many looked to other and more formal ways of drawing the attention of the doctor to themselves, and holding him or her to account for both a perceived medical failure, and a breach of trust. In Chapter Three I described medical culture as an inhibiting factor to admitting to an error, a question of personal and professional embarrassment, with implications for medical indemnity insurance as well as Hospital based employment (Friedson 1975, pp. 136; Bosk, 2003, Preface xIx). The cultural norms, and a different sense of accountabilities, by doctors are of little consequence to patients who suffer an AE and want acknowledgement in the first instance.

“Accountability” for participants was a journey of discovery as to how their AE had occurred, and uncovering the “truth” about it. By formally lodging a complaint, HSC and VMIA participants typically sought recognition of the harm caused to them; accountability by the doctor responsible; and an assurance that doctor practice would improve and hospital systems would change for the better. The reason most participants gave for taking part in my research study was to throw light on a perceived failure by a doctor(s) and the hospital system. Many participants wanted to ensure that there was learning from the AE so that other patients did not suffer.
Figure 5: Desire for Accountability

- Unambiguous acknowledgement of error by the clinician who has to face up to the suffering of the other
- To uncover the "truth" as to what or how injury happened
- "Punish" poor performance to facilitate
- "Protect" other patients in the future
- Change the hospital "system"

- The Doctor "learning" from the mistake in a personal sense
- "Regulation" of the medical profession in a similar way to other industries such as the trades
The formal processes disappointed most participants who embarked on them, because their expectations were out of alignment with reality in that a formal process was not going to deliver a personal acknowledgement by the doctor. A process is, after all, a process, with a set of rules and formalities with which participants have to comply. The capacity to tell one’s story in one’s own way is limited. In the case of out of Court settlements, the matter is handled as between lawyers and insurers, meaning there is no personal engagement as between the complainant and the doctor concerned. Confidentiality Agreements signed as part of the legal and financial settlement (James, Margaret, Ros, Carolyn) meant that participants could not speak to anyone about the doctor who had caused their AE.

“Accountability” from a patient perspective required:-

- an unambiguous and personal acknowledgement of error and harm caused by the doctor;

- the discovery and disclosure as to what happened, and how it happened;

- a process by which poor performance by doctors would be the subject of investigation and disciplinary action taken as required. It was assumed that this would facilitate learning from the AE in a personal sense by the doctor and also encourage greater transparency in and regulation of the medical profession, which many participants perceived as being a “closed shop”;

- a better outcome for others in the future.

Accountability for participants involved personal acknowledgement of harm caused by the doctor concerned, but also a sense of assurance that lessons had been learned from their particular AE by the doctor concerned, as well as the Hospital as an institution (Vincent, 1996, pp. 1609). Participants felt let down by both the doctor, and the hospital system, that had allowed it to happen (Refer: James; 52; VMIA: 1st interview, Chapter 7, Reflections)
Hospital participant Jane wanted accountability, and sought to take legal action, but abandoned the idea when she was reminded that she would have to pay the Hospital’s legal expenses as well as her own, if her case was unsuccessful. Jane used the words “learn” and “learned” 16 times in our second interview, reflecting her hope that the doctor would change her practice and improve her performance following the AE. Jane was not convinced that this would be the outcome.

“If she’s learned and doesn’t make the same mistake with someone else well then something good would have come out of it (her AE). But as long as she has learned. But whether she has or not is very hard to say. Everyone’s got to learn by their mistakes but she should have been more accountable for it (AE). I hope she got her ass kicked big time over it. And then maybe she would have learned.”

Jane; 48; Hospital: 2nd interview.

Legal action was “one way of getting attention [and] they would change the system and not let it happen again.” was Ros’ expectation, adding that as an individual she felt unable to speak up, to be a lone voice, vis-à-vis the doctor and the hospital system, without back-up support. However, this did not occur:

“And then the third meeting was the settlement day. I sat in that room and they went up there and settled. I never got to put my case to anyone. I never was able to speak to the hospital representatives, or the doctors. It was settled and you sign this confidentiality statement and that was it. You’re just hushed up. So it’s hush money isn’t it? They just pay you to get out of the way. So it’s [legal process] not meeting any purpose”.

Ros; 60; VMIA: 2nd interview.

**Participant’s life/work experience and expectations of accountability**

The apparent lack of accountability of doctors bewildered participants who had to comply with rules and standards in their everyday lives. Drawing on her own experience as an owner/operator in the hospitality sector, Jennifer observed that the health and safety standards and regulations that she was obliged to follow were very
strict: the source of food supplies, dates of purchase, everything had to be documented, and “if something goes wrong you’re got to honour it and tell the truth”. Jennifer concluded that her initial surgeon did not meet her standards or expectations.

“He wasn’t prepared to be made accountable for what he did. He fobbed it off by saying ‘look you’ve got a problem in your mind’. [I was thinking] you’re not dealing with the problem at all. You don’t even want to know about the problem. I guess they’re [doctors] being careful because they know that they can be sued but at the end of the day they should have a duty of care for their patients.”

Jennifer; 57; HSC: 2\textsuperscript{nd} interview.

Anthony observed-

“From a tradesman’s point of view there’s an actual code of practice that’s supposed to stop dodgy operators. I see no reason why there shouldn’t be [one] in the medical trade. There should be someone watching them [and] making them accountable for any mistakes. I mean they’re pillars of society supposedly and people are in the palm of their hand. They could have a good day or a bad day but if the bad outnumber the good they shouldn’t be doing the job.”

Anthony; 41; Hospital: 2\textsuperscript{nd} interview.

Brian worked in a heavily regulated industry where accountability to consumers was paramount and breaches attracted significant fines.

“The medical profession [should] be more accountable for the things that are intangible now such as their opinions. I certainly don’t want it to become an Americanised legalised system where the doctors are too afraid to even have an opinion but they do need to be accountable for their service provision as in any other profession, as in my profession.”

Brian; 41; HSC: 2\textsuperscript{nd} interview.
The Fourth (and Default) "A": Anger

Expressions of Anger

Hospital
- Feeling "toothed off" or that there has been a cover up of a perceived medical error
- Still not knowing what or how the AE happened
- Real life losses experienced

VMIA
- Cover up of an error
- "The Hospital "system" allowed it to happen"
- The legal "process" disappoints

HSC
- "Experiences of powerlessness"
- "Lack of accountability, the Doctor is still "getting away with it"."

Real life losses experienced

VMIA
- "Perceived as important"
- "Lack of support"

HSC
- "Lack of acknowledgement of error from the Doctor"
- "Lack of accountability, the Doctor is still "getting away with it"."

Real life losses experienced

No Change in the Hospital "system"
Anger is the default emotion of my 4As. Anger arose for participants when there was a lack of acknowledgement by the doctor of the harm that they had suffered. The literature about patient experience of AEs does not directly report this response; rather it concentrates on patient satisfaction with the OD process. Neither Iedema et al, nor Mazor, in their studies of patient responses to apology and disclosure when things go wrong, reported anger as a primary response. This may be partly related to the timeframe of the studies. These studies only interviewed patients on one occasion, whereas my study involved two interviews over time, allowing participants time to realise and articulate their anger.

Two Hospital participants (Mary and Carol) were angry at the first and only interview that I had with them, because doctors came and went, and didn’t pay attention to them. Jane became angry over time. The majority of HSC participants (10 out of 12) were relatively swift in lodging a complaint with the average time lag between the date of the incident and reporting it being 4 months, indicating something about their emotional resolve to take action as well as their resourcefulness in knowing what to do and where to go. Brian and Jennifer were exceptions taking 3 and 2 years respectively before contacting HSC, as they persevered in efforts to have their medical conditions corrected by the original treating doctor. The majority of HSC participants felt let down by the process because it did not deliver an acknowledgement by, and accountability for, the doctor concerned. Seven of the 12 HSC participants subsequently explored legal options. Anger typified the responses of 5 of the 6 participants in the VMIA group at the first interview and it had not abated for 3 of the 4 continuing participants by the time of the second. Most VMIA participants took a year or more before contacting a lawyer reflecting medical conditions that required further procedures. They were shocked and angry that the hospital system had allowed their AE to occur and then angrier still with a legal process that failed to deliver any sense that the doctor had been held accountable for the error. At the time of the first interview, between 5 and 9 years had elapsed since the AE though in the case of 4 participants one could be forgiven for thinking that the AE had happened only recently such was the intensity of feeling and distress displayed in the interview(s). The real life losses experienced by many participants, across the three groups, both physically and emotionally, were significant.

For the majority of participants, the lack of acknowledgement of the harm caused to them, and ownership of the error by the doctor concerned was the major concern. Vincent referred to the trauma caused to the patient by the perceived lack of appreciation of the severity of an AE on the life of an individual (Vincent, 1994, p.1609). The formal processes typically compounded participant’s experience of an AE. In the absence of a proper acknowledgement, participants
whose medical condition had been resolved remained angry; participants who had been financially compensated for their AE remained angry. Some participants who had received a form of apology remained angry. Participants felt abiding anger because:-

- there had been a lack of acknowledgement of error; they felt “fobbed off” and suspected there had been a cover up of the facts;
- the “system” had failed them;
- the doctor hadn’t been brought to account; there was no disciplinary action taken or sanctions applied as a result of the AE;
- the complaint and legal processes had disappointed; there were no outcomes arising from them which would lead to changes in doctor behaviour and changes in the hospital system for the benefit of future patients;
- participants continued to experience real life losses as a result of the AE in terms of physical and/or mental well-being, with future life options seen as having narrowed or been completely altered.

I have referred to Brian in preceding Chapters. He spoke about one of his follow-up consultations with the surgeon:-

“[I was] getting quite annoyed because I was not getting the sense he was particularly caring about this. I was clearly pissed off because I was in a lot of pain and wasn’t sure where I was going and what was happening. I didn’t quite get the empathy: I would have expected him to give me comfort but he was quite standoffish.”

Brian; 41; HSC: 1st interview.

“I think his comment was ‘oh, you’ll forget about the pain’. And you do forget about the pain but I’ve not forgotten that comment”.

Brian; 41; HSC: 2nd interview.

Janet discovered, initially through the HSC and then confirmed by Court documents, that “her” surgeon had not performed the surgery, rather a trainee. She could not understand how this could have been allowed to happen.
“I mean if you go to theatre for a major operation you’re entitled to know who is going to be operating on you. That made me angry, really really angry: the thought that they can do that to you”.

Janet; 60; HSC: 2nd interview.

Anthony had also been offended when he learned that Dr P. had not “closed [him] up”.

Six years after the AE, James was “still gravelly aggro, greatly aggro”. (Australian vernacular, meaning angry, aggravated, or a combination).

The lack of accountability played on James’ mind:-

“This is what hurts and annoys so much, that this pretty high up neurologist can still treat people and his duty of care obviously leaves a lot to be desired otherwise he would not have admitted guilt. And he’s just going on willy nilly about his business, his life hasn’t been affected and yet he can still affect someone else. And the system allows him to do it. He hasn’t been held accountable. All that’s been done is his insurance has compensated: his insurance premium’s gone up”.

James; 52; VMIA: 1st interview.

**The 4A Model**

Healing and forgiveness in an AE sense, as distinct from curing a medical condition, can be straightforward. The first and defining vertical axis point of the 4A Model is that between acknowledgement and anger: without the former there will be the latter. This represents an expectation on the part of patients, grounded in the Western medical model, of a doctor and patient relationship of trust. The horizontal axis is between apology and accountability: either one or the other or both can be received, but still leave the patient unsatisfied and angry because both, again in the Western medical model tradition, have become processes, and typically involve agents of the doctor concerned rather than the doctor, him or her self.

I begin with a set of five diagrammes. The first (figure 7) is the simple version of the
4A Model. The next 3 diagrammes (figures 8-10) map the responses of each participant group against each of the 4A points, where a zero indicates no response and a 5 the strongest possible response. The fourth diagramme (figure 11) maps the combined responses of all participants, across groups, against each of the 4A points. I make a number of notations in the diagrammes. A dash (–) indicates unavailability for a second interview. There were 12 participants who fell into this category. The principal reason for unavailability (9 out of 12) was that the participant was no longer contactable at the address and on the telephone number they had at the time of the first interview. There were 2 participants that I chose not to re-interview. Vic had an angry disposition and I did not feel comfortable in his presence. Fiona’s mental health concerned me and I did not want to cause her distress by asking her to speak about her AE again. Doris declined to participate because she was mourning the recent death of her husband. A zero (0) indicates a lack of response by the participant on a 4A point. A plus sign (+) beside the name of a participant indicates family involvement in the interview(s). Family members in these cases were the principal reporters of the AE, the participant having little or no memory of events, owing to the severity of his/her condition at the time.

Taken as a whole, these 5 diagrammes demonstrate the underpinning and the logic behind the 4A Model. The majority of study participants fit the 4A Model which provides an interpretative framework for understanding the critical interrelationships between the 4As that lead to healthy and forgiving or angry outcomes following an AE.
Figure 7

A Simple Version of the 4A Model

Acknowledgement

Apology                      Accountability

Anger
How well the Hospital Group fits the 4A Model

Acknowledgement

- Anthony: 1/5
  + Ken: 5/5
  + Lionel: 0/4
  + Mary: 5/-
  Carol: 5/-
  Jane: 0/5
  Mark: 5/-
  Bruce: 4/4

Apology

- Anthony: 1/5
  + Ken: 5/5
  + Lionel: 0/4
  + Mary: 5/0
  Carol: 2/-
  Jane: 0/5
  Mark: 5/-
  Bruce: 4/4

Accountability

- Anthony: 1/5
  + Ken: 5/5
  + Lionel: 0/4
  + Mary: 5/-
  Carol: 4/-
  Jane: 0/5
  Mark: 0/-
  Bruce: 0/0

Anger

- Anthony: 1/5
  + Ken: 5/5
  + Lionel: 0/4
  + Mary: 5/-
  Carol: 5/-
  Jane: 1/5
  Mark: 0/-
  Bruce: 1/0

Key:
- (dash): denotes unavailable for a second interview
- 0 (zero): denotes no response on the 4A axis
- + (plus): denotes family member(s) present during the interview
How well the HSC Group fits the 4A Model

Acknowledgement
- Brian: 5/5  
- Carolyn: 5/5  
- Wilma: 5/3  
- Jennifer: 5/5  
- Janet: 5/5  
- Fiona: 4/-  
- Anna: 5/-  
- Norma: 5/-  
- Hugo: 5/-  
+ Len: 5/4  
- Germaine: 0/-

Apology
- Brian: 5/5  
- Carolyn: 5/5  
- Wilma: 4/3  
- Jennifer: 5/4  
- Janet: 5/5  
- Fiona: 3/-  
- Anna: 4/-  
- Norma: 2/-  
- Hugo: 2/-  
+ Len: 2/-  
- Germaine: 0/-  
- Vic: 0/-

Accountability
- Brian: 5/5  
- Carolyn: 5/5  
- Wilma: 5/4  
- Jennifer: 5/5  
- Janet: 5/5  
- Fiona: 4/-  
- Anna: 5/-  
- Norma: 5/-  
- Hugo: 4/-  
+ Len: 5/4  
- Germaine: 5/-  
- Vic: 5/-

Anger
- Brian: 4/4  
- Carolyn: 5/5  
- Wilma: 4/4  
- Jennifer: 4/4  
- Janet: 5/4  
- Fiona: 4/-  
- Anna: 4/-  
- Norma: 5/-  
- Hugo: 3/-  
+ Len: 4/5  
- Germaine: 5/-  
- Vic: 2/-

Key:
- (dash): denotes unavailable for a second interview  
0 (zero): denotes no response on the 4A axis  
+ (plus): denotes family member(s) present during the interview
How well the VMIA Group fits the 4A Model

Acknowledgement
- James: 5/-
- Ros: 5/5
Christine: 5/5
Margaret: 5/5
Michael: 4/3
- Doris: 5/-

Apology
- James: 5/-
- Ros: 4/5
Christine: 5/5
Margaret: 3/4
Michael: 4/3
- Doris 5/-

Accountability
- James: 5/-
+ Ros: 5/5
Christine: 5/5
Margaret: 5/5
Michael: 5/5
- Doris: 5/-

Anger
- James: 5/-
- Ros: 5/5
Christine: 5/5
Margaret: 5/5
Michael: 5/3
- Doris: 3/-

Key:
- (dash): denotes unavailable for a second interview
0 (zero): denotes no response on the 4A axis
+ (plus): denotes family member(s) present during the interview
Figure 11

**Combined 4A Analysis**

**Acknowledgement**

1st Interview
- 18 at 5 on scale
- 3 at 4 on scale
- 21 out of 33 scored high or very high

2nd Interview
- 9 at 5 on scale
- 3 at 4 on scale
- 12 out of 17 scored high or very high

**Apology**

1st Interview
- 10 at 5 on scale
- 5 at 4 on scale
- 15 out of 33 scored high or very high

2nd Interview
- 8 at 5 on scale
- 4 at 4 on scale
- 12 out of 17 scored high or very high

**Accountability**

1st Interview
- 17 at 5 on scale
- 4 at 4 on scale
- 21 out of 33 scored high or very high

2nd Interview
- 2 at 5 on scale
- 2 at 4 on scale
- 4 out of 17 scored high or very high

**Anger**

1st Interview
- 12 at 5 on scale
- 6 at 4 on scale
- 18 out of 33 scored high or very high

2nd Interview
- 8 at 5 on scale
- 5 at 4 on scale
- 13 out of 17 scored high or very high
The Interrelationship of the 4 A’s: Pathways to Anger or Resolution

In this section, I describe how the 4A Model words dynamically, and captures the experiences of the majority of participants. The diagrammes in Figures 12 and 13 respectively show the two applications of the Model. The first is the diagramme showing a lack of acknowledgement. This was the experience for two thirds of study participants. The lack of acknowledgement by the attending doctor, ‘my doctor’, or the hospital system more generally, was a source of disbelief, grief, and anger for participants following an AE. Acknowledgement is the central axis. Participants received an apology, but without acknowledgement it was not heard as sincere, rather a form of words. Participants notionally received accountability, and specifically the VMIA group in terms of a financial settlement, but this did not satisfy, and indeed was not the reason that they took legal action in the first place. Monetary compensation for their future needs was a component of motivation. However, the lack of acknowledgement of harm caused, prompted participants with the personal capacity and resources to take legal action successfully, but this did not provide satisfaction.

In Chapter 4, I observed that participants had both high expectations of, and levels of trust in their treating doctors. It is to be expected therefore that when things go awry with treatment, that patients will have high level needs, physical, emotional and psychological (Vincent and Saunders, 2005, p.5). Giddens concept of “ontological insecurity” provides a basis for understanding this reaction, in that patients’ basic assumptions about the quality of care they would receive from doctor and the hospital were turned upside down. An important aspect of this is an expectation of relationship with the doctor, such that the doctor will remember the patient, and the error, and support them through a difficult time. This requires acknowledgement of the error to the patient directly, in a personal, face to face sense. Illness can knock one off balance, one’s life trajectory is not going according to plan, but an AE constitutes another and surprising blow because it challenges the patient’s expectations that he or she would be looked after in their illness. Making sense of this extra, unforetold event is important for patients, and doctors can help them on their journey by being involved and being direct. In Chapter 4, Cassell described
what he considered to be the opportunity, and responsibility, of doctors to play a leading role by witnessing suffering and distress, and to “walk” with the patient, in these moments, with attention and empathetic listening (Cassell, 2004, pp. 287). While Cassell was writing in the context of illness, his advice could not be more pertinent for doctors who are dealing with patients who have suffered an AE: a direct and open intervention can save a great deal of suffering for all concerned, doctor included (see Figure 13).

Participants were damaged by an AE in many ways and the lessons learned from it were often hard ones. Faith and trust are words that keep recurring in these patient stories describing the hope and expectations associated with their medical and hospital care. These words offer a context for the disillusionment that may follow an AE. All participants began in a trusting way and that expectation typically imploded with an AE, if not exactly at the time, but over time. The fracturing of trust often has longer term implications. Some HSC and VMIA participants tended to assume retrospectively a degree of responsibility for what went wrong often citing their lack of research or knowledge prior to a procedure or failure to seek a second opinion. For many HSC and VMIA participants an AE not only fractured their trust in the medical profession and the hospital system, but often led participants to experience a second “AE” by virtue of their disappointment with the formal/legal processes that they had chosen. I described the experience of a number of participants who had taken action in several forms in Chapter 7, Section 2, reflecting their initial aspirations and subsequent disappointment and disillusionment with formal processes. Participants generally spoke of being more wary in approaching medical care in the future. Some participants had ruled it out all together.

I begin with the 3 Pathways to Anger, reflecting the unmet needs of participants under each A. Most participants feature on more than one Pathway, whilst often placing a particular emphasis on one or two As over the other(s). I have interpreted through the patient stories that I have been privileged to hear as part of my research that acknowledgment is the most pressing of patient needs, a vital part of recovery from the shock of an AE. Pathways to Anger, 1 to 3, culminate in a diagramme labelled ‘Lack of acknowledgement in Figure 12. In the next 3 Sections, I describe Pathways to Anger by my participants.
Pathway 4 in the Model offers resolution for 2 patients following an AE. I argue that an acknowledgement by the doctor to the patient who has unintentionally suffered at the hands of the doctor as a result of error will result in the patient being forgiving, if the doctor is upfront and does not hide behind medical indemnity insurance and hospital protocols in a defensive way, difficult though that may seem for an individual practitioner working in a collegiate or hospital environment. This defensiveness is counter-productive, but can be understood in the context of professional peer group pressure, that may inhibit a doctor from openly admitting to an error (Freidson, 1975; Bosk, 2003), as described in Chapter 3. In addition, Fein (2005) documented the personal and individual factors that may cause a doctor to be reluctant to disclose an error (Fein, 2005 p.489).

**Pathway 1 to Anger: Lack of acknowledgement by doctor**

The lack of acknowledgement of the patient as a person who had been harmed by the doctor concerned was the pre-eminent Pathway to Anger and a precipitator to action for the majority of participants.

Participants for whom lack of acknowledgement by the doctor was a key issue were James, Ros, Christine, Margaret, Brian, Carolyn, Wilma, Jennifer, Janet, Anna, Norma, Hugo, Len, Ken, Mary, Carol and in the second round of interviews included Anthony, Pam and Jane. I included Mark and Bruce in figure 13 respectively, not because they experienced a lack of acknowledgement, rather because they placed a high level of importance on it and because they had received it in a transforming way.

Participants experienced a lack of acknowledgement when it was felt that:-
1. they had not been recognised as a person (more than a patient) who had suffered harm;
2. the impact on their lives and that of their family had been ignored;
3. their concerns about their health and post operative outcomes had not been taken seriously: they had not been listened to; and
4. the doctor involved in their care had not admitted error nor faced them with an explanation as to what happened and why. This was also reported by Mazor, 2013; Iedema 2011, Micalizzi and Bismark 2012; and Vincent and Coulter, 2002.
In Chapter 6, I indicated that many Hospital participants were very ill and/or preoccupied by their physical vulnerability at the time of the first interview. As a result, only 3 participants, Ken (through his wife), Mary and Carol expressed any anger about their AE. Mary received an OD intervention for which she was grateful because it enlightened her as to what had gone wrong in her procedure. She felt strongly however that the surgeon responsible for her AE should have been the one to come and speak with her and explain what had happened. Of the trio, only Ken participated in a second interview but his wife, his spokesperson, maintained her rage. With the passage of time and living with the consequences of their AEs, four other participants, Anthony, Jane, Lionel and Pam had become focussed on the need for an acknowledgement of the harm they had suffered. Anthony and Jane were angry. Whilst Lionel and Pam did not register as angry per se I believe they still fit the paradigm. Lionel was totally mystified about what had happened to him, describing himself as “disappointed and disillusioned” rather than angry. However, had he had more information and understanding, “if I knew exactly what happened, if I knew that things were being hidden from me, I would be onto it. That’s why I haven’t been angry”, there would have been a different response. As an emotion, anger needs a focus and Lionel didn’t have one. For Pam, anger was not an emotion she would claim; rather she lived in the sub-category of resignation. Her life experience had been such that she accepted as her fate that bad things happened to her, and felt impotent in the face of this apparent inevitability.

The lack of acknowledgement of themselves as having been harmed by a medical error without personal and proper recognition by the doctor concerned, irrespective whether there had been a pre-existing relationship with the doctor, was the primary motivating factor for James, Ros, Christine, Margaret, Michael, Brian, Carolyn, Wilma, Jennifer, Janet, Fiona, Anna, Hugo and Len either taking legal action or lodging a complaint. There were many instances where participants returned to the doctor after initial surgery worried that something was amiss and had their concerns dismissed. This was a further aggravating factor for Ros, Christine, Margaret, Brian, Wilma, and Jennifer as the doctor denied their reality and by implication that a mistake could have been made. Jennifer was the only participant to actively seek out another surgeon: the others persevered with the initial doctor, telling themselves that he knew their case, until such time as another health crisis precipitated the intervention of a second clinician who correctly diagnosed the source of their problem and linked it back to the original surgery. Whilst this was greeted with relief by participants as a validation of their instincts and better judgement, which some had begun to doubt, the fact that the AE had dragged on for them had been costly in every sense of the word. Not one of these participants received any acknowledgement of, or apology
for, the suffering they had endured by the responsible doctor. This was particularly poignant for Christine who had been consulting the doctor, a gynaecologist, since the birth of her daughter 20 years earlier. Her profound need for an acknowledgement, apology and a full explanation was expressed in both interviews:

“I really liked (name of doctor) before but when I go through the pain every day I wish he felt that pain himself. If he came when he found out I was so sick in hospital: he should have just rung me and said ‘I’m sorry I ignored you (dismissing her concerns) for 6 months’. If he had said those words I would never have done anything (taken action). That would have been enough for me”.

Christine; 50; VMIA: 1st interview.

“Satisfactory (outcome) for me would have been that Dr (name) would have found out that I’m really ill and all that. He could have sent me a letter saying, look unfortunately something happened. This is what happened. Whether it was out of his control or whatever reason, he could have said ‘I’m so sorry that this has happened but come and see me and we can have a chat’. And then he could have told me what he had done”.

Christine; 50; VMIA: 2nd interview.

Christine concluded the second interview with the following observation:

“I know him for 20 years and I had a very good faith in him (Doctor S) and I trusted him. Yes I should have done some research. My fault was that I put all my faith into that one (first) doctor. I shouldn’t have put that faith in there because of what I experienced is telling me you should never ever put that trust in one doctor Even if you know them for so many years because they could be having a bad day. Maybe they’re not listening to what you are saying because they’re in a rush. You really can’t put any more trust in them. You don’t know whether you’re a number or a patient. They think of you as a number and that’s very sad to think.”

Christine; 50; VMIA: 2nd interview.

The first Pathway to Anger according to my 4A Model is a direct line (the axis) from acknowledgement, or lack of, to anger, from top to bottom, a central line.
Christine had a long-standing 20 year relationship, with the gynaecologist who had delivered her daughter into the world. When Christine felt that she had a medical problem that required investigation she went first, and naturally, to the doctor she knew and who had been part of her life. The surgery went very wrong. Christine’s gynaecologist of 20 years was unable to acknowledge the injury she had suffered, was unable to acknowledge her as a person, his patient, who had suffered. Christine said in both interviews, over 3 years, that all she wanted was for the doctor whom she had known and trusted, to admit that he had made a mistake, and to her, Christine personally: that would have made the difference. She would never have taken legal action otherwise. (Refer: quotes from interview transcripts in Chapters 6 and 7).

**Pathway 2 to Anger: Lack of apology by doctor**

Apology is a subset of acknowledgement of the patient by the doctor. There are 2 groups on this Pathway: participants who did not receive an apology, being the majority; and those who did receive an apology but rejected it because it lacked both a personal acknowledgement of the harm caused to them, and that an error had been made, by the doctor concerned. Both groups remain aggrieved.

Participants were able to differentiate between and describe good and bad apologies, including those who had not received one in any form. The essential elements of a good apology embraced the aspects of personal acknowledgement outlined in Pathway 1. Specifically, participants wanted:

1. an acknowledgement of the themselves as a person who has been harmed during their hospital stay and by the doctor concerned;

2. personal ownership of the error by the doctor and the provision by him/her of a full explanation; and

3. a heartfelt sorry, that is, one which the patient/participant heard as genuine, opening up an opportunity and occasion where they could choose to forgive the doctor and resolve the AE in their minds.

Responsibility for the AE outcomes of participants was often deflected by their doctor and explained in ways other than personal responsibility. Two participants initiated one or more
discussions with the doctor, expressing concern about their procedures and the outcomes. The doctors repeatedly denied that the participants had legitimate concerns: Jennifer was told that it was ‘all in the mind’ and Janet felt that “he couldn’t have cared less”. Ros received a telephone call from the surgeon who had caused her AE, indicating his preparedness to “follow her up” if she cared to make an appointment but “there was no apology or anything.”

Many participants referred to a lack of apology, which I re-interpreted within a framework of acknowledgement as meaning a lack of genuine and heartfelt apology by the doctor to the patient personally. I referred to Christine in the preceding section, and to Andrew and Cathryn extensively in the next Chapter. In this section, I want to draw attention to the participants Jane and James, both of whom have been mentioned on numerous occasions from Chapter 6 to the present. Both participants received an “apology” and rejected it as lacking the heartfelt remorse, and admission by the doctor of a personal error, which was what they needed at the time. Jane and James wanted a level of reassurance that there had been “learning” on the part of the doctor and the hospital system, but that was lacking. (See quotes from Jane and James in Chapters 6 and 7 respectively.) Mazor noted that words, albeit of apology, were not enough in the case of cancer patients who had suffered a medical mishap; there needed to be a clear connection, congruence between the words proferred and the perceived outcomes in terms of learning from the experience, and changes made to medical and legal practice (Mazor et al. 2013, p.314).

**Pathway 3 to Anger: Lack of accountability of doctor**

There has to be accountability in order for participants to feel that the harm they had suffered has been acknowledged. Participants were shocked that their doctors continued to practice after the AE as before, with no apparent consequences or changes in behaviour. Neither formal nor legal processes were seen as bringing them to account. Participants commented on their sense of the medical profession being a closed circle, with doctors unwilling to testify one against the other in support of a patient.

Under the heading of accountability, participants articulated a range of needs and expectations. Specifically, they wanted:

1. an unambiguous acknowledgement of error on the part of the doctor and for he/she to face up to their suffering;

2. to uncover the truth as to what and how the AE had happened;
3. to punish poor performance if appropriate by way of disciplinary action and/or closer regulation of the medical profession; and

4. to ensure that the doctor had learned from the AE such that he/she would not make the same mistake again and/or require that system changes had been made within the hospital environment which would militate against the possibility of similar AEs in the future.

Hospital participants for whom accountability was a key issue were Ken, Mary, and Carol and in the second interview included Anthony, Pam and Jane. I refer to Anthony in Chapter 9. Jane used the words “learn” or “learned” over 15 times in the second interview reflecting her hope that the doctor had been brought to account in some way but she was not convinced that that would be the case.

“If she’s learned and doesn’t make the same mistake with someone else well then something good would have come out of it(her AE). But as long as she has learned. But whether she has or not is very hard to say. Everyone’s got to learn by their mistakes but she should have been more accountable for it (and) the hospital. I hope she got her ass kicked big time over it. And then maybe she would have learned.”

Jane; 48; Hospital: 2nd interview.

All HSC and VMIA participants were concerned about the lack of accountability on the part of doctor, notwithstanding their taking action. The shared view was that the doctor had “got away with it”. Many commented that by making a complaint they were offering a service to others, in terms of contributing towards AE prevention, as well as endeavouring to make good the AE for themselves. Their disappointment and disillusionment was acute when it was realised that the legal or complaint process would not result in the doctor responsible for their AE being held to account and to them personally, by way of acknowledging harm caused and admitting error. Even where a doctor did admit liability, it was within the context of his/her medical indemnity insurance, rather than to the participant directly which was, from their point of view, completely unsatisfactory. As I noted in Chapter 7, these formal processes and the expectations that participants attached to them, often compounded the AE experience resulting in a second “AE”. Participants did not feel heard, rather had delivered themselves up, unwittingly, into another process which they did not control. The lack of accountability of the doctor was galling to Jennifer.
and Carolyn. As Jennifer said:

“The thing that made me angry was that he was still doing that sort of thing (making mistakes). And he’s actually trained someone else and (name of her second surgeon) is still getting botched jobs coming to him from that area. For me, it (HSC process) hasn’t solved the problem. This particular doctor has retired but he’s trained someone else in his place.”

Jennifer; 57; HSC: 2nd interview. Similarly, Carolyn

complained:-

“Until the time we moved over here (relocation) he was advertising for patients in the Bendigo paper. Advertising as an ENT for patients. I felt like putting an ad right beside his. (The legal process didn’t satisfy) because he didn’t have to do anything anyway. I don’t know if anything comes out of this so that he actually gets reprimanded. That he’s still getting away with it: that annoys me.”

Carolyn; 30; HSC: 2nd interview.

Ros and Michael reached similar conclusions about the efficacy of legal action to bring about accountability and change.

“And then the third meeting was the settlement day. I sat in that room and they went up there and settled. I never got to put my case to anyone. I never was able to speak to the hospital representatives, or the doctors. It was settled and you sign this confidentiality statement and that was it. You’re just hushed up. So its hush money isn’t it? They just pay you to get out of the way. Because when your motive is to try and prevent it happening again. If you’re not talking to the people involved and I guess it’s only their solicitors that are in there representing them, you’re not getting your story across to anyone. So it’s not meeting any purpose. It doesn’t have any effect. It doesn’t happen to make anybody stop and think: we won’t do this again.”

Ros; 60; VMIA: 2nd interview.

Michael expressed his disappointment as follows:-

“Like they’re saying they don’t know how it happened: that’s the thing that stills plays on you. (The
fact) that they never really found out what happened. ‘but it’s happened, bad luck, move on’. I don’t know whether they did much investigation on their side. It’s probably happened again since then.”

Michael; 49; VMIA: 2nd interview.

Jane spoke for Anthony, Brian, Carolyn, James, Christine, Margaret and Michael when, lamenting the difficulty of bringing doctors to account, she concluded:

“It’s very hard to get a doctor to go against another doctor. Doctor’s won’t go against other doctors. I think a lot of people don’t (lodge a complaint/take legal action) because it’s just so hard to go against the medical profession. Like I said, they stand by each other.”

Jane; 48; Hospital: 2nd interview.

James, referred to in the preceding section, received an “apology” and “accountability” in terms of a successful legal action against the surgeon he had chosen. James experienced other AEs, in the form of an apology that he heard as formulaic, as he describes in Chapter 7, and subsequently a legal process that was demanding and at times, demeaning. James did not receive accountability because his family actually witnessed the surgeon who had caused his AE, admitted and settled through insurance mechanisms, visiting another family member. Accountability was impossible to come by for James, and it had been a hard journey for him and his family, along the way. Nothing had changed for the doctor or the health system as a result of James’ best effort, his AE, and his personal suffering. This phenomenon, of patients still feeling that there has not been accountability, notwithstanding as successful legal process, was not found by either Mazor et al., 2013 or Ledema et al., 2011.
Figure 12

Lack of Acknowledgement

No Acknowledgement

“Apology”
Without acknowledgement, apology may be given, but it is not heard as sincere.

“Accountability”
Without acknowledgement the process is not personal, this results in no satisfaction.

Outcome is Anger
Pathway 4 to Healing and Resolution.

This Pathway is the inversion of Pathways 1 to 3. Two participants, Mark and Bruce, had doctors who acknowledged their AEs and responded to their needs. The doctors:

1. acknowledged that their patient had been harmed by a medical procedure;
2. took personal responsibility for the error;
3. offered an apology which was heard as sincere and one of feeling; and
4. acted straight away to rectify the error and restore the patient to health.

The openness and honesty of the doctors transformed the AE event for Mark and Bruce into one where there was mutual regard and forgiveness on their part. In the one interview that I had with Mark, through an interpreter, he explained that he was not going to blame anyone. The “young” doctor, the Registrar, had said he was sorry. During the time Mark was in intensive care his wife and daughter were impressed and comforted by the fact that this doctor visited many times checking on his progress. This was an important piece of news for Mark too as he began to recover. He was satisfied that the younger doctor took the AE “to his heart” and from his point of view that was the end of the matter.

“He came to explain that they needed to operate for the second time but it was difficult for him to say that because he was there for the first operation and at that stage he said that I needed to have only one operation. Most of the time the younger doctor took the (AE) more to his heart. It was harder for him what happened and so he took most of the time to explain it to me.”

Mark; 45; Hospital: 1st interview.

Bruce emphasised in both interviews that he was “very happy” with his care. Whilst he admitted to feeling “annoyed” when first told that he would need another operation, the open and straightforward manner of the doctor enabled him to reconcile the AE in his mind as a mistake and therefore something he could forgive.
“Yes, good or bad, tell the truth, what’s going on, what’s happened. Everybody makes mistakes. Especially the doctors; they’re tired, working late, but they do the best that can be done. They told me that a mistake has happened: that’s everything for me. I’m not going to shout ‘why you did that’.

Bruce; 48; Hospital: 1st interview.

It is chastening to reflect that of my 34 participants, only Mark and Bruce found a pathway to healing and resolution that was facilitated by a doctor.

The 4A Model: An Outcome of Resolution

The preceding analyses reveal that acknowledgement by the doctor of harm caused to the patient, followed by an apology and accountability, allow a patient to arrive at a point of resolution about their AE. Mark and Bruce were the only participants to have a healing outcome in this sense: for them the notion of lodging a complaint or taking action against their doctor was inconceivable. Mark, who was one of the Hospital participants who did not receive a disclosure intervention, in fact received something that he valued highly: the spontaneous and full explanation as to what had happened from the junior treating doctor. Mark formed the view that the doctor was very upset that an AE had occurred:-

“He came to explain that they needed to operate for the second time but it was difficult for him to say that because he was there for the first operation and at that stage he said that I needed to have only one operation. Most of the time the younger doctor took the (AE) more to his heart. It was harder for him what happened and so he took most of the time to explain it to me.”

Mark; 45; Hospital: 1st interview.

Mark went on to say that he would have been angry if he had not received an explanation but the fact the doctor had apologized in a way that Mark understood as completely genuine-“he took it to his heart”- was more than sufficient. This is an excellent example of the elements that I argue are required in order to constitute
acknowledgement of harm caused and a ‘good’ apology. Mark’s doctor came to explain that he needed a second operation because the first one had failed. Mark told me that when he returned from ICU his wife and daughter told him that “the doctor was coming many times to be with me”. The care and attention he received and the remorse he observed in the doctor enabled him to conclude that:-

“There is nothing bad I can say about anybody”.

Mark; 45; Hospital: 1st interview.

Mark had an opportunity on both a cognitive and emotional level to forgive the doctor and felt perfectly satisfied with his care as a result. Mark and Bruce both received an explanation as to what had happened and responded in a reflective way. Neither attached any blame to the doctor.

Similarly, whilst Bruce admitted to being “annoyed” when he was told that a “mistake” had been made during his operation and that a second one was required he nevertheless concluded:-

“Everybody makes mistakes. It’s a mistake you know but you can’t stop that. But I mean the doctors do the best that can be done”.

Bruce; 48; Hospital: 1st interview.

Mark and Bruce both received an explanation as to what had happened and responded in a reflective way. Neither attached any blame to the doctor.

I had the opportunity to interview Bruce twice, and his position remained the same: he had been “annoyed”, initially featuring on the “anger” axis, but becoming less by the second interview. He was reconciled with the doctor’s explanation that a mistake had been made. The second operation had restored him to health, and after all, “everyone makes mistakes”.

The spontaneous acknowledgement of an AE, personal engagement by their doctors with Mark and Bruce enabled them to perceive their AE as regrettable, but part and
parcel of the risks of medicine: “there is nothing bad I can say about anybody” was a view that Bruce and Mark shared, the only two participants out of 34 to come to that conclusion.

The pathway to healing and resolution following an AE requires a personal connection with the doctor, in the form of acknowledgement, apology and accountability. Other studies have highlighted the deficiencies of an open disclosure protocol (Iedema et al., 2011; Mazor et al., 2013).

In Figure 13, “Acknowledgement Encompasses Apology and Accountability”, I show the patient and doctor dynamic again in diagrammatic form. The central feature is acknowledgment, which leads to resolution for a patient following an AE. As experienced by Bruce and Mark, an acknowledgement of one to the other of an error, albeit unintentional, carries with it, even if not explicitly stated, an apology and ownership of the mistake, a personal sense of responsibility, which opens up the possibility of forgiveness, one to the other, and resolution.

**Summary of Chapter**

In the preceding two chapters, I gave an account of the patient experience following an AE, drawing on their own words, interpretations of events, and reflections. In this chapter, I have sought to abstract the personal to a 4A Model, which encapsulates the needs of patients following an AE, being first and foremost acknowledgement of a patient as a person who has been harmed by their medical and hospital care, one to the other, by the doctor concerned. Apology and accountability are important constituent elements of an acknowledgement, but neither will suffice on a stand-alone or combined basis, with a personal acknowledgement of error, and personal engagement with the patient. An Open Disclosure practice has been in place in Australia since 2008, but has failed to meet the needs of patients (Iedema, 2011). My 4A Model gives the reason why: it fully represents the voice of patients, their authentic voices, following an AE, rather than concerns about the delivery of a process.
Figure 13

Acknowledgement Encompasses Apology & Accountability

Acknowledgement

Apology

Accountability

Outcome is Resolution
Chapter 9:

Case Illustrations of the 4A Model

“Whether I shall turn out to be the hero of my own life, or whether that station will be held by anybody else, these pages must show”

(Dickens Charles, David Copperfield, para 1)

Introduction

In Chapters 6, 7 and 8, I used quotes extensively, though selectively, to illustrate the breadth and depth of the impact of an AE on participant lives. My purpose in using Case Illustrations in this Chapter is to give the reader an opportunity to hear an AE story, in a fully coherent way, as told by participants, and gain an overall sense of the person whose life had been impacted. I will set out the stories of Margaret, Carolyn and Anthony over all other participants for three main reasons. Firstly, I had a complete data set for the three, having conducted 2 interviews over a three year timeframe. Secondly, the data was rich, each person was able to articulate what the AE had meant for them in a life context and why, in different ways, they were still engaged by and with it. Thirdly, these 3 cases demonstrate the complexity that an AE introduced to ordinary lives, which is otherwise invisible. From the outside, there would be no evidence to indicate that any of these participants had ongoing issues arising from the AE.

Margaret and Carolyn had sued over the AE. They had battled their way through unfamiliar, and at times, hostile legal terrain. Carolyn had worked her way through a failed complaint process to a successful legal outcome. An observer could have concluded that with a successful legal outcome, the AE had been resolved as far as they were concerned, but this was not the case. Neither woman reached resolution. It would have made a profound difference to both women if there had been a personal acknowledgement from the doctor that they held responsible and accountable for their injuries and damage “some kind of personal
acknowledgement, rather than just a process”, but no such acknowledgement was offered. Both women made the significant and life changing decisions not to have another child because of their AE experience, internal damage and fear of further complications. In Anthony’s case, his decision not to complain, or take action could have been interpreted, at a superficial glance, as if the AE was not an ongoing issue for him, but nothing could have been further from the truth. The lived experience of sequential AEs was an emotional burden that Anthony struggled to contain: “the bitter pill that I’m continuing to swallow”. Margaret and Carolyn were left feeling that “nobody gives a damn really”, that is, the doctors who had failed them. Anthony continued to hope, and wait, for the attention of his doctor. The data from the interviews shows the AE experience from the inside. In this sense, Margaret, Carolyn and Anthony best illustrate the 4A Model. They began by wanting an acknowledgement by a doctor, and went from there on their individual journeys, but the journey did come back to tors, associated with unfulfilled wishes and expectations associated with a doctor.

Words and phrases in quotation marks are those used by participants.

**Case Illustration One: Margaret**

“My world changed as a result of that experience and the way I see it”.

**Introduction**

Margaret’s AE occurred simultaneously with the birth of her first and only child. A “careless cut by an unknown surgeon” changed the future lives of Margaret and her family. It was a defining moment. She was a new Mum entering into a world of sleep deprivation, trying to meet the needs of her colicky baby son whilst being unusually drained of energy and always ill. Margaret had an anal fistula, but it took 3 years and three failed surgical procedures for her to discover that she had had an AE (anal sphincter muscle cut) during an episiotomy procedure and childbirth. It was irrecoverable time for her: the first few years of her son’s life when she felt retrospectively and sadly that she had not been the Mum that she had hoped to be because she was always battling her own body with continuing infections. Whilst meeting the basic needs of her baby, Margaret felt that this was not how she had
envisaged being a mother to her first-born. Margaret expected more of herself than this, and more for her son: more than she had experienced as a child in terms of attentive love and care. The AE deprived Margaret of the quiet and settled family life she had envisaged for herself in a rural idyll.

Margaret’s mother migrated to Australia from the U.K when Margaret was 6 years old, leaving behind her half sister whom she did not know. They moved around metropolitan Melbourne as her mother took on various positions as matron of children’s hostels for the Anglican and Uniting Churches: “Frankston to Noble Park to Elsternwick to just all over the place.” Her mother, who was unnamed (as was her father) in her story was then appointed matron or director of a place that Margaret described as a half-way house for girls, or rather, a home for troubled adolescent girls aged between 14-18. Margaret survived the relocation from the U.K and the dislocation in terms of moving around “homes” when in Melbourne. She told me that she grew up “fast” and by the time she was aged 10 was making decisions, and generally looking after herself. Margaret used the word “streetwise” to describe herself at that tender age as a badge of honour: she was going to be a survivor. Margaret’s sense of personal agency was high because she felt that she had to look after herself, hold herself together, and had done so during many life changes. Margaret saw herself as an independent and self-reliant woman. Margaret married at the age of 18, but within 6 months, her husband was dead. She told me this during our second interview.

After 10 years in a self-described “whirlwind” of emotion and depression, an “emotional wilderness”, Margaret rebuilt her life carefully and quite literally. Margaret re-located to rural Victoria with a new partner, and moved into a mud brick house they built themselves. The energy and determination required to build a mud brick house on a slope, in a relatively remote location, suggested a sense of purpose to me when I visited, and offered an insight into Margaret’s character and determination. Margaret’s intention was to put down roots, settle, and build a life for herself and a family. She had survived dislocations as well as a personal tragedy without much emotional support from others. Margaret mentioned her mother only fleetingly, by way of a background story, and there was no reference to friends, which is perhaps not surprising given the moves that her mother’s job required.
Margaret’s new home, the one that she and her partner had constructed, represented a fresh start for Margaret as she anticipated the birth of her baby, within a rural community, situated in a natural, as distinct from an emotional, wilderness. The peace and tranquillity Margaret had envisaged changed because of her AE: it was a tragic turn of events, and winter set in again for her, metaphorically. Normal life, the things that she took for granted, including sex “went out the window”. She was physically damaged, and afraid. Margaret had not needed to engage with the medical community very much prior to her pregnancy, and her AE experience meant that she wasn’t going to put herself in that position again, willingly. Margaret made the life changing decision not to have a second child because of her fear that another pregnancy could trigger total faecal incontinence as distinct from the partial incontinence she suffered from the AE. The three surgical procedures she had undertaken to remedy her condition had failed to do so and Margaret couldn’t contemplate a fourth medical procedural failure. It would “do her head in”. Margaret had been advised that complete incontinence was inevitable without a surgical intervention and that she had to confront her “demons” in terms of fear and loss of trust. When she felt emotionally ready to proceed, Margaret wanted to make sure that she had “the best doctor that money could buy”. At an intellectual level, Margaret knew that there were surgeons with the requisite skills but she didn’t know how to identify them. Presumably there would be someone in Melbourne. Her GP had not helped with his prior referrals, which had resulted in three failed surgical procedures. Margaret no longer trusted the GP’s judgement. However, when her son suffered from ear infections and needed antibiotics in the middle of the night, Margaret’s choices were limited. It was either the local hospital which was 15 minutes away but where she felt labelled as a troublemaker and where her GP may be the duty doctor, or drive another 30 minutes to the next town. In Chapter 6, Margaret remarked that she and her partner would only visit the doctor if “they were dying”, but her son’s needs took precedence. The life choices for Margaret were to stay in this particular community, uncomfortable though it had become because her GP and the hospital had been enjoined in Margaret’s legal action, or re-locate and re-build again. Margaret was stuck, and she knew it.

Margaret and acknowledgement
Margaret’s GP failed to acknowledge her AE, other than obliquely by providing the medical referrals for the follow-up surgical procedures. Whilst he wasn’t there at the time the AE occurred, nor responsible for it in any way, he was nevertheless Margaret’s doctor, and key medical advisor leading up to the birth of her son. He was the one that she continued to consult after the birth searching for answers about her tiredness, infections, and leakage. Margaret’s GP was her initial and ongoing point of contact but he had not been able to bring himself to talk to her about her AE, name it as such with her. That which could not be spoken about constituted an overhanging cloud on their doctor and patient relationship. Margaret gave him opportunities to talk about her condition, well before she understood it to have been caused by an AE, when consulting him about her son’s ongoing ear infections, but he didn’t take them up. Instead, Margaret left his surgery feeling patronized, concluding that the GP thought she was “stupid”. Margaret had to manage her feelings about the GP because of where she lived and the limited medical options available, if her son needed care urgently. Nevertheless, Margaret felt that her GP had let her down badly, and his failure to acknowledge her ongoing health concerns and unwillingness to talk about them openly and directly created a huge barrier between them.

Margaret received an actual acknowledgement that she had suffered an AE for the first time when a solicitor friend of her partner recommended that she take legal action, and put her in touch with a Melbourne law firm. She did the requisite rounds of medical appointments in order to establish the facts of her medical condition and it was during one of these consultations that the doctor confirmed to Margaret that during the episiotomy a “wrong cut” had been made. The woman solicitor who was handling Margaret’s case got “fired up” about her situation. Margaret felt empowered for the first time in a long time, as she was finally in possession of the facts. She felt that she and the solicitor were on a mission together to address her issues but in so doing helping to ensure that other women did not suffer the same fate during childbirth. Margaret’s sense of purpose proved to be short-lived. When the solicitor left the firm and a male colleague took her place, Margaret was on another downward trajectory, as the “mission” became a legal process that took her on a journey that she hadn’t expected. She had assumed that her legal action would bring the “the crew”, that is those directly responsible for her AE at the second hospital to account, but instead it opened up a Pandora’s box for Margaret as every member of
the local medical team including her GP were enjoined in her action. This created a huge undercurrent in Margaret’s life. She worried about the assumed back chat about her, and wondered if there would be recriminations, if and when she sought medical treatment. She encountered members of the local medical community in her everyday life and she experienced many awkward moments, even in the simple act of going to the supermarket. Margaret had not intended to “blame” these people, yet they had become involved in the legal process around her AE. This was a very different outcome from the way Margaret had expected her new life in the country to unfold. Rather than be an accepted member of the local community, part of the furniture as it were, Margaret had to negotiate her way again, and all because of a lack of care and attention on the part of a” faceless “ surgeon.

**Margaret and anger**

In our two interviews, Margaret became very emotional and angry as she reflected on her AE. It was the tidal surge of anger that surprised her most. Generally speaking, Margaret had thought she that she had dealt with the emotional issues surrounding her AE. She had dealt with challenging life issues before. However, the interviews revealed to Margaret the depth of her unresolved feelings. The emotions that were stirred up during our first interview were even more pronounced in our second when she broke down crying, before recovering herself. Margaret told me that she had been apprehensive about agreeing to a second interview. In my work in pastoral care dealing with bereaved women, I had on many occasions observed the cumulative effect of grief and loss, which is to say that each new experience of grief and loss often opened up old wounds. Margaret had suffered a major bereavement when she was 18 when her husband of 6 months died. She had rebuilt her life and had been looking forward to family life with her new son. As Margaret said, all she had wanted was to “bring him home and love him”. The AE changed all of that for Margaret. She felt that for the first 3 years of her son’s life she was not fully present for him, preoccupied as she was with her own ongoing health issues. She had wanted to focus on him, rather than herself. Nothing could compensate Margaret for the loss of these early years with Max, certainly not a compensation payment. Margaret was angry and profoundly sad because she felt she had neglected her son emotionally at his most formative stage. It was eerily familiar with the way she herself
had been brought up, and this was not what she had wanted or expected for him. The very big cubby house, with the sign Max on the door, did not take away or compensate Margaret for the hurt inflicted by the AE.

Margaret gave vent about her disillusionment with the medical profession and her frustrations with the legal process that had not resolved her issues around the AE, indeed had complicated her life even more. The doctor/specialist she was referred to by her legal advisors wasn’t prepared to stand up in Court and tell others what he had told her during a consultation, which was that her AE had been caused by the single cut, a wrong cut, during childbirth. Margaret’s legal case folded at that point, and after so much time, effort, and perseverance on her part she entered into mediation, there being no other alternative. It all seemed so pointless to Margaret. She had tried to look at the AE from all angles, to see if she could discern why she had “attracted” it into her life. There was no meaning, spiritual or otherwise, that she could detect. The only things she learned, as she said in Chapter 6, was that surgeons were addressed as “Mr” as distinct from “Doctor” and members of the legal profession, namely barristers, “wore funny hats”. Margaret wasn’t going to trust either the medical or legal professions again. The ontological insecurity, as described by Giddens, remained a feature of Margaret’s life.

Margaret turned her back on Western medicine, until such time as she could face her “demons”. She put up her shingle as a “natural therapist”, with rooms in town. Her main clientele were the tourists that came to visit, but she hoped there might be a few locals seeking alternative remedies. Margaret’s life took another tragic turn with the AE, but she intended to get on with it. Margaret was not going to live in a perpetual wintry state emotionally She had done that already.

**Case Illustration Two: Carolyn**

“*He made me want to pursue it just so that he gets into trouble. Why should he get away with it?*”

**Introduction**

Carolyn was a young mother of two living in country Victoria when her AE journey
began. It had seemed so straightforward at the time. She suffered from recurrent tonsillitis and her GP recommended that she have her tonsils removed. He placed her name on the elective surgery waiting list of the main, local, public hospital. A short time thereafter, to her surprise and delight, she received a telephone call at home from a man who introduced himself as an ENT surgeon from Melbourne who had consulting arrangements with a number of country hospitals. He had noticed Carolyn’s name on the waiting list and offered to expedite her surgery if she agreed to travel to a branch hospital. Carolyn thought this was a wonderful opportunity: “get straight in, get it over and done with”. Post operatively, Carolyn suffered significant bleeding and required hospital admissions to the main hospital and another branch hospital over a two week period. The surgeon, on his post-operative ward round, and the only time Carolyn had seen him in person had advised her that if she had any difficulties following surgery, she would need to go to a hospital, other than where she had been admitted, because it didn’t have back up or emergency facilities. Doctors at the main base hospital did not want to become involved in her care because she was not their patient. Attempts made by doctors, and by her GP, to contact the surgeon by telephone and pager to request his attendance were unsuccessful. The Resident Medical Officer (RMO) at the base hospital did manage to speak with him once but he declined to visit Carolyn, which left her, and the RMO, frustrated and angry. The RMO subsequently filed a report with the hospital. The bleeding subsided but Carolyn continued to experience great difficulty eating and drinking. After 5 months Carolyn consulted an ENT in private practice who diagnosed that her soft palette had been damaged during the tonsillectomy. He performed surgery and Carolyn’s swallowing difficulties were greatly relieved, though she had to be careful. Carolyn’s life changed significantly over the course of the three years between our interviews.

**Carolyn and agency**

Carolyn lived in a small community where everyone knew that she was sick, going to and fro to various hospitals, with neighbours and Carolyn’s parents being called upon to baby sit at short notice. People were concerned for her and Carolyn’s condition became a community talking point. She was encouraged to take action of some sort and Carolyn felt that there was no point in “whinging and whining” if she
didn’t follow through. She may have felt that her personal credibility was at stake. Carolyn wrote letters to the CEO of the regional Health Care Network and the CEO of the hospital where the procedure was performed. Carolyn asserted that the operation had not been carried out correctly and complained about the lack of follow up care by the surgeon, which she described as below a professional standard. Carolyn was unhappy with the response she received from the Network. When after several months she had not received a reply from the hospital, she lodged a formal complaint with the Medical Practitioner’s Board, complete with an appendix listing dates of procedure, hospital admissions, and consultations with GPs. She sought “answers” she said, and “some assurance that this will not occur again”. A reply came from a new CEO of the hospital, attaching a copy of a hand written fax from the surgeon, in which he asserted that his care of Carolyn “could not be faulted”. Further, he stated that Carolyn, as a public patient, had unrealistic expectations of him, noting that the relationship between a patient and a private practitioner was “obviously closer”. His responsibility “lay with the 110 outpatients and 25 surgical patients I was dealing with over that 3 day period” being the period that Carolyn was in hospital receiving 4 units of blood and IV antibiotics and when the on duty Doctors had tried to contact him. Carolyn was deeply offended by the remarks, concluding that the surgeon regarded her as “lower class”, yet remembering that it was he who had contacted her, offering a service, touting for business. The perceived rebuff and lack of acknowledgement of her as a patient who had been harmed, and who had felt abandoned, prompted Carolyn to take the further step of contacting HSC. This proved to be an unhelpful experience. An HSC officer asked her what she wanted to achieve from her complaint. Carolyn replied that she wanted to report the surgeon and “get him into trouble”, receive an apology from him for the harm caused her, and to get the money back that she had spent trying to fix her problem. Carolyn didn’t feel that HSC were taking her complaint seriously, which was confirmed from her point of view when she received a call from an officer notifying her that the case was being closed. She didn’t have a case evidently that HSC would take forward: it was all “in her head” apparently, and “a mere coincidence” that she suffered bleeding following her tonsillectomy. The HSC officer said he was a mediator, didn’t take sides, but nevertheless was closing the case.

Carolyn was “peed off” by the lack of acknowledgement of her, and the failure by
HSC, as a consumer agency, to assume the role of her advocate versus the surgeon
and the hospital. The HSC process was “hopeless” from her point of view.

Our first interview concluded with Carolyn saying that she did not know what the next
step was in terms of bringing the surgeon to account. By chance, by luck, she had
met up with a cousin at a family Christmas gathering who observed that she had lost
a lot of weight since he last saw her, 14 kilos to be precise. Carolyn explained that
she had had her tonsils out and hadn’t been able to eat or drink normally since. The
cousin offered to refer her case to a friend for legal analysis. Carolyn was already
significantly out of pocket as a result of the second operation and couldn’t afford to
lose any more money. The very good news at our second interview was that the
solicitor had agreed to represent Carolyn on a “no win, no fee” basis. A solicitors’
letter of request for documentation elicited a report from the private ENT specialist
Carolyn had consulted. When Carolyn had asked him to put in writing his advice to
her that the tonsillectomy had caused her harm he declined, reflecting the general
unwillingness of doctors to go against other doctors. However, he also said that if
requested formally he would always tell the truth. Fortunately for Carolyn, the
specialist agreed to provide an expert opinion and with that she won her legal case,
and received a significant compensation payment. As with a number of other
participants, the compensation payment did not satisfy Carolyn. The AE had inflicted
enormous stress and strain on Carolyn and her family and she had invested much
time and effort in assembling her case against the surgeon. Carolyn told me that she
got angrier as time went by. In several discussions with members of her community
she discovered other errors that he had made and he was “still getting away with it”!
The legal process hadn’t resulted in any reprimands or consequences for him so far
as she could see. He hadn’t been called to account, indeed continued to advertise in
the local paper, offering his services. Carolyn warned one friend off from contacting
him but worried about the other potential patients who wouldn’t know about his
record, and could be at risk. Whilst Carolyn had hoped that the surgeon would suffer
in some way for the harm he had caused her, she doubted that his conscience had
been pricked by events or that he had felt any remorse for making such a “boo boo”.
If the surgeon had admitted his error to Carolyn, apologized and promised that it
wouldn’t happen again, Carolyn would have been content. All that she had wanted
from the outset was for the AE to be recognized by him.
Carolyn and the irony of her AE

Three years after our first interview, Carolyn was still angry as hell with the surgeon, frustrated that he had not been brought to account, and worried about other members of the community who might suffer at his hands. This much of her story was unchanged. The intervening, successful, legal settlement had done nothing to satisfy, or remedy her fundamental concerns, but she hoped that because of her action the surgeon had been compelled to take notice of her. The surgeon’s failure to respond to and care for her post operatively at the time constituted in Carolyn’s view a lack of common decency and moral fibre. Carolyn felt compromised that she had had to resort to legal action, not generally approving of people who sue, but she had to follow through, and take on the surgeon.

Carolyn’s life had been changed in a negative way initially because of her AE, but it ended up having a positive impact and influence on her life. Carolyn and her husband had planned to have four children, and Carolyn had envisaged herself as a stay at home Mum. After the AE, Carolyn resolved never to enter hospital voluntarily again which meant no more babies. Before the AE, Carolyn had never left her children in the care of others. When her hand was forced, during the 2 weeks that she was going in and out of hospital, Carolyn was relieved that her two children coped very well without her. The enforced time out of mothering, and her observation about her children’s well-being, gave Carolyn an opportunity to contemplate a different life for herself. She decided to undertake further study and subsequently entered the workforce on a full-time basis. Carolyn learned many skills about advocacy and resourcefulness because of her AE, but it had been a hard way to learn. She said she was much more wary and questioning after the AE, amazed in retrospect to think how naive she had been in taking the surgeon’s offer of services at face value. Carolyn, through her own determination and resolve, brought about an outcome for herself, less than satisfactory admittedly, but an outcome nevertheless, following her AE. She had persisted with hospitals, doctors, professional bodies, complaint agencies and finally, a legal process that ended in her favour. Her narrative changed between interviews, reflecting the way in which she had grown into Burnham’s active patient model described in Chapter 4. As discussed in that
Chapter, achieving this role requires persistence and determination, not easily realised by most patients in hospital. Carolyn discovered a personal sense of agency through her response to the AE. However, it was a costly way in which to acquire new skills. Carolyn equated her AE journey with the death of her sister and the birth of her children as the life events that had had the most impact.

**Case Illustration Three: Anthony**

“The apology would be nice, a human touch. It puts the shoe on the other foot too. I mean it’s up to me to accept the apology and that’s only if I think it’s a heartfelt thing. I wouldn’t accept a “well, I’m sorry”.

**Introduction**

Anthony’s reflection about his AE evolved over the three years between our interviews. He had a begrudging acceptance of the AE when I interviewed him in hospital. He felt that his surgeon whom he spoke about on a first name basis had informed him of the risks but perhaps not sufficiently. Whilst he could ask the question “why me” he didn’t feel that would be productive. Anthony didn’t want to complain either, given that this was his first stay in hospital: he didn’t relish being labelled as a “whinger” by his surgeon or the hospital staff because if he was going to need further treatment he didn’t want to be discriminated against, identified as a potentially problem patient. Anthony had chosen Dr P to be his surgeon quite specifically, and according to his own criteria, of friendliness and potential mateship, in order to feel comfortable facing surgery for the first time. Three years on Anthony had ongoing physical problems: the remedial surgery that was meant to address the initial AE had resulted in a second AE. Anthony continued to wait for Dr P to restore their relationship by giving him priority on the surgical list to address the second AE, as had been promised. Anthony remained puzzled, and impatient as to why Dr P wasn’t honouring the moral contract that he felt existed between them.

**Anthony and agency**

Anthony began his AE journey on a positive note. He decided to take action, having been diagnosed with diverticular disease. It was an option about timing from his point
of view rather than emergency surgery, though surgery was going to be inevitable at some point. Anthony’s working life was such that he travelled about and rather than his condition control him, he wanted to be proactive and master it. Anthony did his due diligence and working regularly in a hospital environment as a tradesman, he was familiar with the names of doctors and specialists in the South East region of Victoria. He used this knowledge to help him, in conjunction with his GP, to identify potential surgeons. Anthony then “interviewed” two: the first surgeon that Anthony consulted presented so far as he was concerned as aloof, proposed radical surgery, and was not a person that he could warm to, or raise a smile with, which was his way of initiating relationships. Anthony then consulted Dr P and from his point of view, they “clicked”. Dr P had the credentials as a senior surgeon and was a person that Anthony could envisage as a “mate”, someone he could meet and greet in the street, maybe have a beer with, potentially a “fishing buddy”. Anthony’s expectations of Dr P were high in terms of relationship and trust, and justified in terms of objective evidence of clinical credentials and expertise. This underpinned his trust in having surgery for the first time. but an AE resulted. Anthony remained trusting at this point, having been informed by Dr P about the risks of surgery but disappointed that it had happened to him. He was quite philosophical in the first instance, but then had niggling doubts because Dr P “fobbed off” his questions whilst Anthony was still in hospital, and had sought to shift the blame for complications from surgery onto Anthony’s prior health management. This was insulting, unbelievable, and Anthony got “crotchety” with Dr P but continued to hope for reconciliation.

Anthony had Dr P under the microscope, but didn’t relinquish his expectation that Dr P would do the right thing by him, eventually. Dr P had a huge emotional hold over Anthony for over 3 years and it had not been resolved by the time of my second interview. Anthony’s physical condition had not been resolved, nor had the relationship with Dr P been restored. Anthony was stuck in a relationship that wasn’t working, but he was afraid to make a change. From his point of view, from a tradesman point of view, there was always a reluctance to finish off someone else’s poor workmanship. He tended to “look down his nose” on that sort of job and he assumed that surgeons reacted in the same way. He didn’t want to be on the receiving end, albeit innocently, of derisory comments and reluctant surgery. He had chosen Dr P and he expected him to “finish the job”. Anthony drew on his own life
experiences to try and contextualize Dr P’s behaviour. If he took his car in to be fixed, for example, and it wasn’t fixed, then he would take it back and it would get fixed: that was the deal. Dr P hadn’t met that expectation. If Anthony was painting the inside of a house, he would “always tackle the corners first” because he knew they were “the trickiest bits”. Dr P seemed not to have done that either, taken extra care knowing that Anthony was a diabetic. Dr P was trying to “cop out” of responsibility insofar as Anthony was concerned. In the time between our interviews, Anthony discovered that Dr P had not “sewn “him up, that is completed the original surgery and there was the thought that poor practice at the end stage of surgery by a junior doctor had caused the original AE. Anthony wondered why Dr P hadn’t been looking over the shoulder of a trainee surgeon, making sure that he, Anthony, was all right, and also why Dr P hadn’t attended to him and fixed up the second AE, the hernia, quickly rather than waiting for 3 years. Dr P, the potential “mate” was missing in action at the time of the original surgery and was evasive in the subsequent consultations that Anthony had about his stoma and further surgical procedures. Anthony continued to wait for the call from Dr P that he was on an expedited surgical list, expecting an explanation, about what had gone before, and an apology.

**Anthony and moral expectations.**

Anthony was “cranky” and/or “crotchety” with Dr P, both words being his euphemisms for angry. Dr P had not behaved in the way that he, Anthony, was bringing up his 3 boys: when you made a mistake, you owned up to it. You said sorry and you meant it, and that would be the end of the matter, provided the apology was genuine. This was a core value for Anthony: honesty, and owning up to mistakes. You could not live with yourself otherwise. Dr P’S failure to acknowledge the harm that Anthony had suffered, accept personal responsibility and rectify the condition tested every aspect of Anthony’s belief system and life. He couldn’t be himself, live his proper life, with the everyday reminder that surgery had gone wrong and it hadn’t been rectified. Anthony’s life, including his relationships with family and friends was tested. Anthony admitted taking out his “crankiness” on his wife Fay when she told him to “please get over it”. He couldn’t get over anything because it was both a physical and psychological issue intertwined with his expectations of Dr P. Fay didn’t seem to understand so far as Anthony was concerned because she didn’t
have the “crook guts” on a regular basis or the unlovely scar that he looked at in the bathroom mirror every morning after a shower. Fay was on the receiving end, as were his mates. They were tolerant for just so long, before they gave him “a punch on the arm”, in a friendly way, and told him to “get over it”.

Acknowledgement of harm caused and an apology from Dr P was what was needed but it had to be a quality apology, not just an “I’m sorry” but heartfelt. Anthony wasn’t going to accept anything less than what was costly in emotional terms from Dr P. The summer had ended, the romance was over, let’s just get it sorted out was how Anthony felt. He didn’t know where or how to start or whether he was brave enough to see it through. It would have been different, he thought, if he had been assaulted in the street. He would have tracked down the attackers through whatever processes were available and demanded an apology. It would have been different, he thought, if the first surgeon he had consulted and decided against had operated on him: he would have given that surgeon hell if he had made a mistake, an AE. The situation with Dr P was more difficult and constraining: Anthony liked and trusted Dr P. The “assault” had happened within a hospital environment where Anthony had begun his journey as a patient with apprehension but also complete trust. Dr P was in charge of this unknown universe. Whilst he now had reasons to doubt Dr P, Anthony also recognised that his own personal power was limited. Anthony felt he needed permission to ask questions about his AE with Dr P and our second interview gave him an opportunity to articulate his concerns and questions. Why was it he pondered that doctors didn’t seem to be accountable to the world for their actions and mistakes, in the way that he understood accountability from his life experience as a tradesperson? Anthony wanted Dr P to apologize to him personally, to admit an error, to acknowledge their moral contract. He was bringing up his boys to do the right thing in the world and he expected no less honourable behaviour from his surgeon. Anthony wanted an opportunity to both confront and forgive Dr P. Anthony was in a holding pattern physically and emotionally until his issues were addressed by Dr P. At the time of our second interview, Anthony was still waiting to hear from Dr. P and I do not know whether the situation was resolved to Anthony’s satisfaction.

**The Outliers**
Introduction

Seven participants, all from the Hospital group, did not identify with any point on the 4A Model. There are a number of reasons for this. Firstly, for five of the seven, I have an incomplete data set in that I was only able to conduct one interview with them. In a number of these cases, the interview took place within a couple of days of the AE having occurred and the participants were very ill. This made it difficult for them to comprehend what had happened, but they grasped the fact that they had been gravely ill and could have died. Participants were immensely grateful to be alive, and that was their main focus: everything else was a second order issue. Across the seven there were also personality and life experience factors, associated with socio economic background and low expectations, which influenced their responses. A short profile on Elsie, Jan, Don, Roger, Justin, Pam and Sam is given below. Only Pam and Sam were available for a second interview.

Elsie- 1 Interview only

Elsie was 58 when I interviewed her, and whilst her life had been a struggle, she didn’t complain. She had migrated from Germany in 1957, at the age of 14, and her mother had placed her immediately into domestic service. Elsie had no formal education after this point, and her English language skills were limited. She relied on her brother, her only living relative, to “interpret” on her behalf, including the interactions with doctors about her medical condition: her husband and only son had predeceased her. Elsie had been in hospital many times before for serious conditions ranging from cancer, heart problems, and diabetes. She felt that she had been well looked after in the hospital, was grateful to be alive, though on this occasion was “scared I might not come out anymore”. Elsie received an OD intervention but found it incomprehensible, saying she was “not good with big words”.

Even if she had grasped the nature and implications of her AE, haemorrhaging on the lung post operatively, I believe she would not have reacted in a 4A Model sense. The AE was simply another episode in a history of struggle to which she had become accustomed. Elsie, dependent and vulnerable, was indebted to the hospital
for enabling her to survive thus far. If Elsie won Tattslotto tomorrow she said, the hospital would receive the first million, because “I’ve been treated very good. I can’t complain”. Elsie died in hospital one month after the interview.

**Jan- 1 Interview only**

Jan was 61, and had been an emergency re-admission to hospital and theatre following a hernia operation. A blockage in the bowel was discovered and Jan was fitted with a stoma. Jan was in a deep sense of shock when I interviewed her, feeling quite overwhelmed by the turn of events. One minute she had been fine, and the next minute she was in ICU with a stoma. She needed time to “sit and think”. Jan had no recollection of the OD intervention, indeed couldn’t remember “one doctor from another”: it was all a blur. Jan was clear about one thing however and that was how grateful she felt for “being here”, being alive. When I invited Jan to rate her experience of being a patient and level of satisfaction with her care on a scale of 1 to 5, with 5 being excellent, Jan did not hesitate: “I would take it to 5 because I can’t complain about anybody since I’ve been here. They have all been very helpful and good to me”. She wondered about how she would manage with the stoma when she went home, back to work, and couldn’t imagine how she would feel about another operation in 6 months time to reverse the stoma. Jan was just going to concentrate on taking things one day at a time. Points on the 4A Model were irrelevant at this juncture in Jan’s life. Three years later when I telephoned Jan to arrange a second interview, she declined, saying she did not want to talk about the AE, adding that she had had to give up her job. I assumed that the AE had had a serious effect on Jan’s life such that she didn’t want to talk about it, maybe bringing back painful memories. Whether Jan would have identified with a point or points on the 4A Model at a second interview is open to conjecture. The data is incomplete.

**Don- 1 Interview only**

Don was 44 when I interviewed him. He had been in hospital sequentially for appendicitis and haemorrhoid problems, before a cancerous tumour was detected. The operation to remove the tumour was successful but resulted in a bleed, a leak, and a haematoma, necessitating further surgery. Don received an OD intervention,
which was consistent with the information he had already received from his surgeon: the haematoma was unfortunate, but a risk associated with major surgery. Don accepted that it was an unforeseen event. He was however concerned about the time that had been taken to identify that he had cancer and do something about it. A lack of information and communication as between Don and his wife and doctors distressed them: it “strung them out”. At this point in their lives, Don and his wife wanted progress in his health care rather than reflection, and the 4A Model had no relevance. Three years later, Don declined my request for a follow-up interview. In a brief telephone conversation, Don said that thinking about the AE, and maybe his medical condition more generally, was “upsetting”, and even being reminded of it by talking to me was “upsetting”. Whether Don would have identified with a point or points on the 4A Model at a second interview is open to conjecture. The data is incomplete.

Roger - 1 Interview only

Roger was 51, and an emergency re-admission. He had been in the hospital before with cancer, and after a bout of pneumonia felt that he had been discharged too soon. He returned to hospital with a second bout of pneumonia. The clinical notes missed the fact that he was undergoing chemotherapy. Roger’s observation about his AE was that he told the medical and nursing staff that he shouldn’t be discharged, first time around, because he didn’t feel well enough to go home. On re-admission, Roger had an OD intervention, which confirmed his sense that things had gone awry, but he wasn’t going to do anything as a result. He appreciated the use of “layman’s language” but he had a good understanding of his condition anyway. Roger was relieved to be receiving care, and gave the hospital and doctors a 4 out of 5 rating on a notional patient satisfaction scale. Roger felt that lack of communication between staff had contributed to his AE, but he was “coming good”, and didn’t harbour any grudges. Roger did not register at any point on the 4A Model at the first interview. My letter to Roger, requesting a second interview, was returned to me as “addressee unknown”. The data is incomplete.

Justin - 1 Interview only
Justin was a man in his early 20s, who had a minor AE from which he had completely recovered, by the time I interviewed him. Justin had an OD intervention and was neutral as to whether it helped him understand his AE. Justin did not contribute to the interview beyond minimalist “yes” or “no” answers. Justin was looking forward to being discharged from hospital, returning home, and getting back to work. I concluded that Justin had agreed to participate in the study because it offered a diversion from the boredom of lying in bed. Justin did not return telephone calls post discharge requesting a follow up interview. There is very little data about Justin.

**Pam - 2 Interviews**

Pam was 73 and “away with the fairies”, to use her words, when I interviewed her in hospital. Our second interview took place at her twin sister’s home, with a cousin present. Most often Pam’s sister spoke on her behalf. They were despairing about what to do and who to turn to for help about Pam’s ongoing medical problem, an abscess and a stoma. Pam had been advised that further surgery was needed but that she wasn’t strong enough to survive major surgery. Pam did not register at any point on the 4A Model. Pam told me that her life had been “ruined”, as a result of the AE but she wouldn’t make a complaint against doctors for fear that next time she needed hospital admission and care “they” being those in authority, would turn her away, by way of retribution. My telephone call to Pam after 3 years had seemed something like a lifeline in terms of information and action about how to manage, and get help, for her ongoing condition. Pam had “given me away”, so said her sister Pat, as just another person who promised, but hadn’t delivered, which apparently was their life experience. They welcomed a second interview, hoping that I may offer guidance and potentially advocacy on their behalf. Pam was “too crook” to do anything herself, and her sister said she had a stutter and did not want to put herself forward, in terms of making a complaint on Pam’s behalf. A lack of resources in a physical, emotional and life experience sense, left Pam stranded. Pam did not receive an OD intervention, though I doubt it would have made a difference. The points on a 4A Model were not on Pam and her sister Pat’s radar, as they struggled to survive in an everyday and practical sense. Pam’s life experience, in a similar way to Elsie, had led her to expect that things would go badly and that she was
powerless to do anything about it. Despair was her ongoing motif.

**Sam- 2 Interviews**

Sam was 73 years old when I first interviewed him. He had been admitted to hospital as an emergency patient with an aneurism on his aorta. He had had a happy and illness free life prior to that, and when he heard one of his daughters talking with a doctor about his condition, which at the time, was precarious, he thought to himself so far as he could recollect that he had “had a good run”. He wasn't going to resent dying. Sam considered himself a “home-spun” philosopher and had “pre-programmed” himself, which is to say rehearsed in his mind how he would react in a range of tragic circumstances, the drowning deaths of children and which one would he save, by way of example. A number of Sam’s work colleagues were shot dead in a mass shooting in Melbourne. Sam had been sailing on the Indian Ocean at the time.

Sam had felt that something was wrong and had agitated with the medical staff until someone took notice of him. Sam got the attention of a doctor on the evening shift, new to his case. Sam convinced the doctor that he had a problem, tests were undertaken and Sam was right. Whilst Sam would have preferred that his AE had been attended to earlier, it had been fixed, and was simply “a little mistake” which in the overall context of his hospital admission was right. Sam could not have been more delighted with his hospital care, rating it as 5 out of 5. Sam was happy to be alive, grateful to have been given another chance at life, another “Spring” as it were. The 4A Model was an interesting theory for Sam to consider. Sam agreed with the worth of apology, being theoretically important but difficult for people to express openly and honestly. Sam is an outlier because of his particular personality, and chosen way of looking at life.

**Summary of Chapter**

In this Chapter I have used three case illustrations to demonstrate the complexity of the impact of an AE in the lives of ordinary people, complications which would go unremarked, unnoticed by an outside observer, because participants would not want
to share their inside story. Margaret lived in a small rural community where everyone knew everyone and unfortunately for Margaret that meant interacting in an ordinary, everyday sense with the health professionals that had not so much as caused her harm, but in the case of her GP, despite promptings by Margaret, failed to acknowledge the harm that she had suffered. Carolyn also lived in a rural community and whilst she was prepared to take action against a visiting specialist, whom she considered had caused her harm, she did not want the fact that she had taken legal action, and successfully, to become known in the local community, because, as a shared community sentiment, she “didn’t like people who sue”. Anthony wanted acknowledgement and an apology from the doctor he had trusted who had let him down, not even “closing” him up. Anthony didn’t want to be considered a “whinger” in his community of family and mates.

In an overall sense, I would place Margaret in the Acknowledgement frame of my 4A Model, Carolyn in the Accountability section and Anthony in Apology as the priority of their concerns, but they were concerned with all of these issues, nuanced by their own perspectives of life leading up to hospital admission. These participants’ shared the inside story of the AE in a holistic way, including their hopes and expectations, the pathways taken and the perceived outcomes. Their stories show the interweaving of the themes of acknowledgement, accountability, apology, which if unresolved led to anger.

In this Chapter, I have also accounted for the seven participants who did not fit the 4A Model and the reasons why this was the case.
Chapter 10:

Conclusions and Recommendations

Introduction

The formal research question addressed in this thesis was: “How do patients experience and understand an AE in the long term?”. The specific objectives were to:

1. Explore the effect it had on their lives;
2. Explore the meaning that they ascribe to it;
3. Investigate the actions taken (or not taken) and the reasons why pathways were chosen;
4. Explore the factors and or interventions that may assist in meeting patient needs following an AE.

In this chapter, I present my answers to the research question in terms of a number of key conclusions. I have discussed my research questions and my findings as an iterative process throughout my research journey, discovering many new insights along the way. I have not seen the need for a Discussion Chapter, per se, because the discussion has been a continuing one throughout my Findings Chapters.

I have come to the view that an AE is not simply something that happens during a hospital stay: it can be life changing and the repercussions life-long. The patient focus in an AE is primarily on the perceived relationship with and acknowledgement by the treating doctor, rather than the actual nature of the AE itself. On this basis, I believe that an OD protocol does not meet the needs of patients because it does not necessarily involve the doctor concerned or address the patient’s understanding of the meaning of the AE. This is important. Patients want acknowledgement and in a personal way. Finally, I offer recommendations for training of medical students, junior and senior doctors about responses to patients who have suffered an AE, in the knowledge that medical errors happen, that patients can be forgiving if given
opportunities to do so, and that the existential and relational concerns of patients can be met.

1: The AE as a life-changing experience

My research involved the journeys of 33 participants who took different pathways following an AE, individually couched, and personally understood. Participants were initially passive in the face of their AE, in the style of the Parsons model described in Chapter 4. Participants did not necessarily understand what had happened to them, and were dependent on a doctor or “their” doctor to explain things to them. Participants reached out to doctors for an explanation, and when that was not forthcoming those with a sense of personal agency took matters into their own hands through official routes, with little success. The desire to be noticed as a patient, as a person, who had suffered a medical error/injury was a motivating force. The injury suffered by the patient as an AE was exacerbated by the absence of the doctor, his or her denial of error, and the frustration experienced by participants as they tried to prove a case against a member of the medical fraternity.

2: Meeting patient needs after an AE

The existential pain of an illness is best addressed in the context of a doctor and patient relationship (Toombs, 1992; Cassell, 2004; Frank, 1995) where the patient is treated as a person with individual needs. I argue that the existential pain of an AE is also best addressed in the context of a doctor and patient relationship, more so because it is an injury caused, albeit unwittingly, but nevertheless suffered, and coming on top of sickness. An AE comes out of sickness, but is an unexpected injury with added consequences for the physical and psychological health of patients. A doctor and patient relationship is difficult to find in the context of an AE: only 2 out of 33 participants managed this. Reporting of error, and even successful legal outcomes, did not lead to satisfactory outcomes for participants. What may appear to an outsider as either success and/or resolution around an AE (for example, a payment as a result of legal proceedings) has a very different sense to the person concerned in terms of their felt experience and the losses they incurred, physically and emotionally, and the implications that has for their life going forward.
3: Open disclosure fails to meet patient needs

OD offers a protocol rather than a relationship, and hence does not meet the strongest need of the patient who has suffered an AE. This is perhaps not surprising, since OD began, and continues, as a risk management tool. There are two specific issues with OD which are highlighted by this study. Firstly, the timing of OD timing needs to be re-considered, because patient capacity to absorb information whilst very sick is limited. OD made little or no difference to hospital participants within the Study, because it was too soon after the AE occurred. Secondly, OD delivery needs to be re-considered, because patients want more than a process or protocol, however well delivered; they need the person they understand as the treating doctor(s) to take responsibility and talk to them individually.

4: Actions taken after an AE

The formal processes of making a complaint or taking legal action disappointed most participants, none of whom had any experience of taking such action prior to the AE under discussion with me. Participants were in unfamiliar territory: their expectations were out of alignment with the reality of a formal process that they expected would deliver acknowledgement, apology, and accountability. Formal processes could not deliver a personal acknowledgement by the doctor, but they did not know that at the time of lodging a complaint or consulting lawyers;

The majority of HSC participants (10 out of 12) were relatively swift in lodging a complaint with the average time lag between the dates of an incident and reporting it being 4 months, indicating something about their resolve to take action as well as a degree of resourcefulness in knowing what to do and where to go in order to make a complaint; The HSC complaint process was experienced as a failure by 10 of the 12 participants who took that pathway. HSC has an assumed mediating role, a quasi consumer advocacy role on behalf of patients, but participants found that it lacked capacity to resolve their issues: it could not bring the doctors face to face with them and mediators were often experienced as annoying and frustrating (Bruce, Cathy). HSC had a mediating role, but lacked teeth in terms of bringing the doctor to account. Seven of the twelve HSC participants subsequently explored legal options: 2 successfully (Cathy and Jill); Wendy was the only HSC participant to have felt helped by the complaint process, saying that she lacked confidence in her own
A successful physical resolution of the problem caused by an AE did give satisfaction to one HSC participant (Wendy) after many years of effort on their respective parts in the face of denial by doctors of their lived illness experience. They were encouraged to doubt and potentially to accept that their physical condition and concerns were problems originating in their heads rather than their bodies. This was a further overlay on their AE. Whilst there was self-doubt, in the face of “expert” medical opinion, there was also persistence and a fashioned resolution.

Entering into a formal legal process was very difficult for VMIA participants, requiring them to present themselves to adversarial lawyers, although not in Court, and medical indemnity insurance doctors, and defend a medical and legal claim under much scrutiny and scepticism. This was a first time experience for all participants. It was a difficult environment and one in which participants felt under pressure in an alien, totally new, world (Ros, Margaret, James).

A successful legal outcome did not translate into resolution of issues around the AE suffered because there was no felt personal outcome in terms of the doctor being brought to account. A successful legal outcome and a physical resolution of the AE did not result in healing for participants, because “healing” following an AE is as much about psychological healing as it is about physical repair, and this requires an acknowledgement by and engagement with the doctor responsible. Indeed, for some participants (Ros, James, Margaret), legal processes compounded the AE experience because they were put under pressure but they did not perceive any good had come from their effort: the doctor continued to practice, unimpeded, the hospital system appeared unchanged: so much individual suffering, but no benefit for the greater good, which would have helped make sense of the AE. It was suffering without a purpose

5: The consequences of the AE experience

There were a number of very significant consequences of experiencing an AE for participants in this study. An AE made participants suspicious about the medical profession, and some concluded that the medical and legal professions were closely
intertwined making it almost impossible for an average claimant, citizen, to win a case against the combined force of the professions. Further, the AE caused some participants to choose not to consult doctors again. For some participants, the AE and its aftermath constituted a fundamental loss of faith and trust in the medical profession: (Margaret, James, Michael, Carolyn). Thirdly, an AE resulted in some participants making life changing decisions, such as not to have another child, and/or not to enter a hospital again voluntarily (Margaret, Carolyn, James).

6: Healing after an AE

“Healing” following an AE requires acknowledgement of error by the doctor to the patient, which creates an opportunity for the rebuilding of trust and relationship. Implicit in acknowledgement is an acceptance of responsibility, accountability for a medical error, and an apology, one to the other, that the patient has been unintentionally harmed. “Healing” is more complex than physical resolution of conditions caused by the AE, or a successful legal outcome: it is about restoration of relationship and trust.

Recommendations

My aim began as and continues to be to improve the experience of patients who suffer an AE during hospital stay. The question is how to improve a medical/legal hospital system which has deep roots and defensive mechanisms. I offer recommendations for training of medical students, junior and senior doctors about responses to patients who have suffered an AE, in the knowledge that medical error occurs, but that patients can be forgiving if given the opportunity by doctors, hospitals, and medical indemnity insurers to do so. The ontological challenge may remain for a patient, with a sense of wariness about the taken for granted assumptions about hospital care. The existential and relational concerns of patients can be met if patients are treated respectfully and as people with a past, rather than simply as patients, by all who come into contact with them during their hospital stay.

Practical Recommendations

1. The timing of an OD process needs to be respectful of a patient’s capacity to
absorb information, and process it, whilst being being very unwell. The dictates of the process must not override the best interests of the patient.

2. An OD process will never be satisfactory unless the doctor(s) concerned in the AE are involved. This will require a re-framing of medical indemnity insurance. If doctors are forthcoming, open and direct with patients following an AE, patients will understand that mistakes happen, but that the doctors’ intentions were good.

3. As part of medical training, greater emphasis needs to be placed on learning to accept failure and mistakes; which is not to say encourage complacency about medical treatment and its outcomes, but rather create a culture in which doctors are prepared to “own” their errors, both to patients and their colleagues.

4. Doctors need ongoing education as to the patient’s perspective of an AE, which differs from a purely clinical evaluation.

Reflections on my Research Findings

My study has brought the patient experiences of an AE to the forefront. My study is not concerned with statistics of AE’s per se, or the best way to deliver an OD protocol to a patient, rather it is about the patient experience of an AE and the way in which patients respond to the AE, and their need for relationship and acknowledgment by the doctor who unwittingly caused their harm.

My study gives voice, literally, to patients who have suffered an AE, but have not felt “heard” by doctors, or in the context of the formal processes that they undertook in order to be “heard”; and have their AE noticed. When I began my research, I was of the view that an OD would satisfy patient’s needs following an AE. I had witnessed that in my role as a pastoral care worker at the Royal Women’s Hospital in Melbourne: in one incident, I saw a couple transformed from anger to acceptance of a medical error, because of the personal presentations of two doctors. The presentations revolved around acceptance of personal responsibility for an AE: in the first case, the doctor deflected, and the patient and partner felt angry and frustrated.
In the second interview, the doctor responsible for the AE came into the room and in an open and honest way, gave an account as to what had gone wrong, and why. My observation of these two doctor and patient interactions following an AE framed my initial understanding as to the benefits of OD.

This was my research starting point, and I have learned a great deal over three plus years of interviews with participants. The opportunity to talk with participants, in two stages, has given me unique insights into the impact of an AE on the lives of the individual concerned. The ripple effect of an AE on life generally has not been mentioned before in the literature, over this period of time, and with the same group of participants. I need to emphasise the time element because between my first and second interviews some participants had taken steps, other had had outcomes, some were still in a holding pattern awaiting a doctor response. An OD did not deliver a satisfactory result for participants, as I had anticipated, because it became a process rather than a personal and genuine encounter as between doctor and patient. The relationship has been overtaken by rules and protocols about what is said, and how it is delivered, as recognised in other studies (Iedema, 2011; Mazor, 2013).

More particularly, participants who had the personal resources to take their AE to the next level in terms of a formal complaint or legal action emerged from the process, were often wounded for a second time, because the doctor had not been called to account, to face them, and explain what went wrong. This is the 4A Model, an extrapolation of my findings, that without acknowledgement by the doctor to the patient, there will always be residual anger and mistrust which is likely to be projected onto the medical community as a whole, the hospital system, rather than just an individual medical practitioner. A form of apology is of little account unless it is personal; accountability is hard to find in a process in which the other main participant, the doctor, is not required to participate in the exchange with the patient other than through legal representatives. The relationship between doctors and patients originated as one of trust and remains so, particularly for older patients. Formal complaints and/or litigation against medical professionals often represent frustration about a lack of relationship and respect. Doctors, patients, and family members need to be mindful that at a particular point of time they are all in the mix.
together, and medical, as well as emotional outcomes, are at stake.
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Author/s: 
Marriott, Patrice

Title: 
Suffering over time: patient journeys following an Adverse Event (AE) in Victorian public hospitals, pathways undertaken, and perceived outcomes

Date:
2016

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http://hdl.handle.net/11343/123676

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