The Psychological Impact of Medical Error: Symptoms of Trauma in Family Members of the Injured

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The Psychological Impact of Medical Error:

Symptoms of Trauma in Family Members of the Injured

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A Thesis in the Field of Psychology

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Abstract

This study examines the impact of medical error from the perspective of the family members of the injured and addresses the questions: Are family members at increased risk of experiencing symptoms of trauma following the medical error injury of a loved one? ; Does disclosure of the medical error mitigate family member response?

Participants in this retrospective case-controlled study represent a population of individuals that report loved ones harmed by a medical error, an affiliation with a patient safety organization, and a desire to participate in research. One hundred twenty-eight family members self-selected to participate in an online survey in response to invitations emailed to the members of six patient safety organizations: Consumers Advancing Patient Safety (CAPS); Persons United Limiting Substandards and Errors (PULSE); Medically Induced Trauma Support Services (MITSS); Consumer's Union (CU) Safe Patient Project (SPP); Agency for Healthcare Research and Quality (AHRQ) Patient Safety Network (PSNet); and the National Family Caregivers Association (NFCA). The survey incorporated quantitative and qualitative measures; specifically, the *Detailed Assessment of Posttraumatic Stress* (DAPS; Briere, 2001), *Physician Communication* scale (PCOM; Heisler, Cole, Weir, Kerr, & Hayward, 2007), a measure for quality of disclosure used by COPIC Insurance (COPIC, 2004, 2007), the *Wake Forest Trust in Medicine* scale (Dugan, Trachtenberg, & Hall, 2005), and two open response questions.

Results indicate that these family members suffer from enduring, emotional duress that diminishes their ability to enjoy life and are at increased risk of PTSD. In this group, 37.5% ($n = 48$) of family members report experiencing symptoms of PTSD with 4.7% ($n = 6$) reporting mild symptoms of trauma, 11.7% ($n = 12$) moderate symptoms of trauma, and 21.1% ($n = 21$) severe

symptoms of trauma. Greater income and more education serve as buffers to trauma and medical errors resulting in more serious injury increase trauma. Trust was greatly diminished as indicated by this group's mean trust score of 9.88 (*SD* 4.21, range 5.00 - 25.00, Cronbach's α = .84) as compared to a mean trust score of 15.00 in another study of a large patient population. More than two-thirds of these family members did not take legal action. No significant correlation was found for any of the communication measures (PCOM, *Disclosure Strategies*, or *Quality of Disclosure*) and taking legal action. This finding indicates that there is not an increased risk of litigation when healthcare professionals communicate with family members and that there is little reason for healthcare professionals to provide anything less than adequate communication. Still, disclosure rarely occurred with 66% (*n* = 85) of the family members reporting no disclosure strategies put into practice by healthcare providers. Overall, 72% (*n* = 92) family members rated the quality of the healthcare professionals' disclosure of the medical error as fair and the *Quality of Disclosure* was negatively correlated with the measures for symptoms of trauma. Specifically, family member reports of *Hyperarousal, Posttraumatic Impairment,* and *Reexperiencing* (r = -.32, p < .001; r = -.31, p < .001; r = -.30, p < .001; respectively) are most influenced by poor quality of disclosure. Qualitative findings supported the quantitative findings. The Harvard Medical Practice Study (1990) found that between 44,000 and 98,000 patients die in hospitals each year as a result of medical errors. Given that each patient likely has two family members that must deal with the consequences of the ordeal, the psychological, social, moral, and personal impact of medical error on the family is significant.

Dedication

This work is dedicated to my remarkably brave mother, Emily Catherine Thomas O'Bryant.

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Chapter I

Introduction

When a loved one is in need of medical care, family members may be concerned about the loved one's illness, may be involved in the loved one's efforts to seek medical care, and may have the added stress of being responsible for providing additional care to the loved one. In addition, family members are emotionally affected when loved ones experience serious health problems, especially when the health problems involve questions of life and death (Anderson & Tomlinson, 1992). A medical error likely makes the situation more difficult.

Available research indicates that both the patient that is injured by a medical error and the healthcare professional that is involved in a medical error often respond with psychological symptoms of trauma. While reports of large numbers of medical errors (Harvard Medical Practice Study, 1990; Mills, 1977; Studdert, Brennan, & Thomas, 2000; Weiler, 1991) increase concerns about the impact of medical error in patients and healthcare professionals, there has been somewhat less concern about the impact of medical error in family members of the injured (Vincent, Young, & Phillips, 1994). However, when patients are harmed by medical error, family members must cope with the consequences of the ordeal. For this reason, the current study investigated the impact of medical error from the perspective of the family members of the injured and addressed the following questions: How do family members respond following the medical error injury of a loved one? In particular, are family members at increased risk of experiencing symptoms of trauma? Does disclosure of the medical error mitigate family member response? If so, how does the quality of that disclosure impact that distress?

Insufficient evidence is available to determine the impact of medical error in family members of the injured; however, interviews of medically injured patients and studies of healthcare professionals' reaction to medical error provide clues that may aid in predicting the emotional response of family members to the medical injury of a loved one. For example, Gallagher, Waterman, Ebers, Fraser, and Levinson (2003) conducted thirteen focus group discussions to investigate physician and patient attitudes regarding medical error disclosure. The fifty-two patient participants were active members of a healthcare service recruited though advertisements. Transcript analysis revealed that patients fear the possibility of errors happening in their care and that patients respond to a medical error incident with feelings of anger, frustration, and depression (Gallagher et al., 2003). In addition, Gallagher and associates' analysis of forty-six physician transcripts revealed that after a medical error, physician's distress was often long lasting and included feelings of shame, fear, guilt, anxiety, a personal sense of failure, and a loss of confidence. Similarly, other researchers report that healthcare professionals commonly express emotional distress after being involved in a medical error incident (Christensen, Levinson, & Dunn, 1992; Waterman, et al. 2007).

Comparable findings were reported by other researchers. Elder, Jacobson, Zink, and Hasse (2005) conducted twenty-four patient interviews and reported that anger and a decrease in trust were the most common emotional responses to a medical care problem, including a medical error incident. In addition, these researchers found that patients' interactions with healthcare professionals changed following medical care problems. Specifically, patients reported avoidance of the healthcare system, more assertive communication with the healthcare providers, and increased insistence on getting a second opinion (Elder, Jacobson, Zink, & Hasse, 2005). Also, Vincent, Pincus, and Scurr (1993) found that distress in one hundred and one patients injured by

medical error during surgery was greater than distress in patients with serious illness, serious accident, or grief in the absence of medical error during surgery.

Given the reported response of patients and healthcare professionals to medical error incidents, it was reasonable to predict that the medical error injury of a loved one may be difficult for family members to endure. Therefore, in this study, it was expected that affected family members would report thoughts, feelings, and behaviors similar to those found in other trauma-exposed populations. Some family members were expected to report reactions including fear, horror, helplessness, guilt, humiliation, shame, dissociation, or detachment from emotions (Briere & Scott, 2006; Herman, 1997). In addition, it was anticipated that over time, some individuals may develop more enduring symptoms of trauma including intrusive memories, emotional numbing, increased anxiety or arousal, and avoidance of situations reminiscent of the experience (Herman, 1997). It was expected that the development of symptoms of trauma would depend on a number of factors including personal history of traumatic events, gender, and the extent and type of reaction experienced at the time of the traumatic event.

Following any traumatic event, individuals are at increased risk for Posttraumatic Stress Disorder (PTSD) as provided in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR; American Psychiatric Association [APA], 2000). To determine the probability of PTSD among those exposed to trauma, Breslau and associates (1998) used questions based on DSM criteria to examine trauma symptoms in a large community sample. Violent trauma (e.g., assault, serious accident), non-violent trauma (e.g., diagnosis with life-threatening illness, discovering a dead body), and secondary trauma (e.g., witnessing the injury of another, learning about trauma to others) were reported in this population (Breslau et al., 1998). Assaultive violence was associated with the highest probability of PTSD (twenty-one percent), while learning about a traumatic event experienced by another was associated with the lowest

probability of PTSD (two percent). Learning about the sudden unexpected death of a loved one was associated with moderate probability of PTSD (fourteen percent). The overall risk of PTSD was nine percent based on multiple traumatic events randomly selected from a list of all reported traumas (Breslau et al., 1998). The findings from this study were thought to be appropriate for comparison to the findings in the present study for several reasons. First, the study by Breslau and associates included a wide range of possible traumatic events an individual may experience in a community. It is likely that the extent of possible traumatic events a family member may experience during the delivery of medical care to a loved one is similarly broad. Second, the study by Breslau and associates included PTSD rates for events that were indirectly experienced by the study participants. When a medical error occurs, the family member does not directly experience the medical error injury of a loved one. For these reasons, it was predicted that nine percent of the family members with loved ones suffering medical error injury would report experiencing symptoms of trauma.

The emotional impact of a medical error may depend on the way the incident is handled afterward. Vincent (2003) asserts that harmed patients respond to medical error injury with symptoms of trauma, and he claims that disclosure strategies used by healthcare professionals after a medical error injury can reduce symptoms of trauma in patients. In this study, it was expected that family members would report less severe trauma symptoms (e.g., no symptoms, mild symptoms *vs*. moderate symptoms, severe symptoms; Briere, 2001) when healthcare professionals used disclosure strategies that included providing facts about the medical error incident, apologizing for the medical error, making an effort to prevent similar errors from occurring, and offering to pay costs of associated care (COPIC Insurance Company 2007; Lamb, Studdert, Bohmer, Berwick, & Brennan, 2003). Specifically, it was predicted that family members' report of less severe trauma symptoms would be associated with family members' report of healthcare

professionals' using a greater number of disclosure strategies. In addition, it was predicted that family members' report of less severe trauma symptoms would be associated with an increase in the reported quality of the healthcare professional's disclosure.

Thus, while research suggests that the individual involved in a medical error is at risk and that the individual's symptoms will be reduced when healthcare professionals put into practice common disclosure strategies, family members have been overlooked, and few studies have considered the impact of disclosure on family members.

Disclosure of Medical Error

Research findings indicate that family members want to be given information about medical errors that occur in the care of a loved one, want to be told of an error as soon as it happens, want information about errors that result in any degree of harm including errors that almost occurred but were stopped by chance, want information about how future errors would be averted, want an apology, want fees waived, and want compensation for harm (Blendon et al., 2002; Gallagher et al., 2003; Mazor et al., 2004). Still, family members generally are not provided with an explanation, an acknowledgement, or an apology (Blendon et al., 2002; Lamb et al., 2003). Moreover, healthcare professionals rarely provide emotional or financial support for family members following medical error (Gallagher et al., 2003). This information suggests that there is a gap between what family members want to happen after a medical error and what actually happens after a medical error.

Although the psychological impact of medical error and the effect of medical error disclosure in family members of the injured have not be examined; available patient data point to an association between an emotional response to the error and the healthcare professional's disclosure of the error (Gallagher et al., 2003; Vincent, Pincus, & Scurr, 1993). According to

Gallagher and colleagues (2003), patients believed that "the way the error was disclosed to them" had an impact on distress (p. 1005). In particular, patients reported increased distress when explanations were "incomplete or evasive" and reported decreased distress when the error was "honestly and compassionately" disclosed as well as when an apology was given (p. 1005). And, Vincent, Pincus, and Scurr (1993) found that surgery patients injured by medical error experienced disturbing memories and greater distress when fewer explanations were provided. In fact, findings from this study suggest an association between the injured surgery patient's emotional response to the error, the health care provider's disclosure of the error, and the filing of a medical malpractice claim. The injured surgery patients who decided to go forward with litigation were more dissatisfied with the explanations than those who chose not to proceed with litigation (Vincent, Pincus, & Scurr, 1993). Family member response may be comparable to the patient responses reported by these researchers.

Similar connections of medical error disclosure to litigation decisions were reported by other researchers (Duclos et al., 2005; Hickson, Clayton, Githens & Sloan, 1992; Mazor et al., 2004). Mazor and colleagues (2004) investigated nine hundred fifty-eight patient views on disclosure where full disclosure included an explanation, an apology, an acceptance of responsibility, and a promise to prevent the error from reoccurring. Patients responded to vignettes describing medical errors and physician disclosure strategies by indicating the likelihood of changing physicians, the likelihood of seeking legal advice, the degree of patient satisfaction, the amount of trust in the physician, and the extent of emotional reaction. The findings from this study suggested that full disclosure increases patient satisfaction, trust in the physician, and positive emotional reaction. In addition, full disclosure was found to diminish the likelihood of changing physicians and to decrease the likelihood of litigation in certain circumstances (Mazor et al., 2004; p. 416). And, in a study of one hundred twenty-seven claimants, Hickson and associates (1992) found that mothers

seeking legal action following perinatal injury filed a legal claim when they perceived a medical error had been concealed, felt the physicians had "attempted to mislead them", failed to receive essential information, felt a need to shield others from injury, and wanted to retaliate (p. 1359). These reasons for filing legal claims suggest an association of inadequate medical error disclosure to an emotional response in family members and to the decision to pursue litigation.

Disclosure of medical error to patients and family members is supported by physicians and professional organizations (American Medical Association 1994; Ethics Manual 1998; Joint Commission on Accreditation of Healthcare Organizations, 2004). And, although a uniform disclosure protocol with definite disclosure strategies has not been developed (Gallagher & Lucus, 2005; Gallagher, Studdert, & Levinson, 2007), models for disclosure of medical error include providing facts about the medical error incident, apologizing for the medical error, making an effort to prevent similar errors from occurring, and offering to pay costs of associated care (American Society for Healthcare Risk Management, 2003; COPIC Insurance Company 2007; Kraman & Hamm, 1999; Massachusetts Coalition for the Prevention of Medical Errors, 2006; Wojcoeszal, Saxton & Finkelstein, 2008). The medical error injury of a loved one may be less disturbing to family members when those providing healthcare put into practice these suggested disclosure strategies.

Secondary Traumatic Stress

Findings from studies of clinicians and of individuals working in helping professions have supported the idea that an individual's experiences and observations while assisting others during or after a traumatic event may be emotionally stressful (Brown & Campbell, 1994; Brown, Mulhern, & Joseph, 2002; Marmar, Weiss, Metzler, & Delucci, 1996; Pearlman & Mac Ian, 1995; Rich, 1997). These studies report that individuals indirectly exposed to trauma experience disrupted

thought processes, depressed mood, and symptoms of posttraumatic stress disorder (PTSD) including reexperiencing the primary victim's traumatic event, avoiding events or thoughts reminiscent of the stressor, experiencing persistent arousal associated with the incident, and dissociating or detaching from emotions in response to the trauma. When circumstances require witnessing, reexperiencing, or handling the tragedies suffered by others, the psychological impact is termed secondary traumatic stress (Jenkins & Baird, 2002). Early studies of secondary trauma indicated that family members experienced emotional duress when concerned about the survivor of a traumatic event (Figley, 1883; Figley & Kleber, 1995). In addition, PTSD should be considered after an individual has experienced, observed, or learned about an event that involves "actual or threatened death or serious injury, or a threat to the physical integrity of self or others" (*DSM-IV-TR*, p.463; McNally & Breslau, 2008). And, an essential component of PTSD is a reaction to an event that includes feelings of "intense fear, helplessness, or horror" (*DSM-IV-TR*; p. 467). Taking into account that some family members may react to the medical error injury of a loved one with intense emotion, it is reasonable to expect that, following the incident, some family members may be subjected to recurring memories of the incident, may become aroused when confronted with medical situations, or may engage in efforts to avoid medical situations (Jenkins & Baird, 2002; Marmar et al., 1996).

In total, the findings of previous research suggest that, similar to patients and healthcare professionals, family members are likely to be at increased risk of developing symptoms of trauma following the medical error injury of a loved one. Moreover, the limited available data suggest that a healthcare professional's response to the medical error may affect the well-being of family members.

Chapter II

Method

This study examined complex issues regarding medical error and the resulting impact in family members of the injured. The following methods were selected to advance the investigation of the questions of interest.

Participants

Participation in the online survey was limited to individuals 18 years of age or older and to only one individual in each family in which a loved one was identified as having experienced a medical error injury between January 1, 1999 and January 1, 2009. Family members of those injured by medical error were invited to participate by an email invitation that included an explanation of the purpose of study and a link to the survey website. Family members self-selected to participate and indicated the relationship to the injured loved one by a survey item (see Measures, below; Table 1). The survey website was accessed by 289 individuals. Of this group, 90 individuals completed less than five percent of the survey and were removed. Also, 71 individuals completed the survey but did not meet the eligibility requirements for participation including 29 individuals that were injured patients, 28 individuals exceeding the Negative Bias Scale cutoff score, and 14 individuals not receiving medical care in the United States. The remaining 128 individuals are the sample of family members meeting the eligibility requirements for this study. This group included 25 males and 103 females. Demographic characteristics of the family members are presented in Table 1.

Individual invitations to participate were e-mailed directly to 4,851 members of Consumers Advancing Patient Safety (CAPS), 1845 members of Persons United Limiting Substandards and Errors (PULSE), and 2000 members of Consumer Union's (CU) Safe Patient Project (SPP). An e-letter including an announcement of the study and a link to the survey website was sent to 10,000 members of the National Family Caregiver's Association (NFCA). An e-news update that included study information and a link to the survey website was sent to individuals affiliated with the Agency for Healthcare Research and Quality (AHRQ) Patient Safety Network (PSNet) and study information was posted on the PSNet website. Individuals affiliated with Medically Induced Trauma Support Services (MITSS) were invited to participate by e-mail and flyer announcements. The number of individuals affiliated with AHRQ and MITSS that received an invitation to participate or an announcement about the study is not known.

The CAPS, PULSE, MITSS, NFCA, SPP, and AHRQ organizations are comprised of healthcare professionals with an interest in preventing medical error and individuals that experienced medical error as well as their family members. However, measures taken to secure the data and to insure participant confidentiality prohibited the collection, recording, or retention of certain information necessary for confirmation of participant status as a family member of a medically injured loved one or verification of the accuracy of the medical error event reported by the participant (see Procedures, below). In addition, because individuals receiving the invitation were encouraged to forward the invitation to others who met the requirements for the study, many participants may not have been members of the afore-mentioned organizations. For these reasons, the number of individuals that are members of these organizations, experienced a medical error, had a family member that experienced a medical error, and were interested in research participation was not able to be determined. Therefore, it is not possible to determine the

survey response rate. However, because the survey probably reached many hundreds of family members, a low response is assumed.

Measures

Demographic information (age, gender, race/ethnicity, socioeconomic status, and level of education) was collected through questions used in previous research (Cleary et al., 1991). In addition, one item asked the participant to indicate his or her relationship to the injured individual (*Spouse, Parent, Child, Grandparent, Grandchild, Sibling,* or *Other*). One item asked the participant to indicate how he or she knew about the medical error (e.g., "I am / was the injured family member's primary care giver", "I was with my family member when he or she learned about the medical error", "I was designated by my family member to receive information regarding his or her health care"). One item determined the health care professional the family member felt most responsible for the medical error (*Physician, Nurse, System,* or *Other*). And, one item established litigation status ("Please indicate whether you or someone else took legal action as a result of the medical error experience of your loved one"). In response to the litigation status item, a participant selected *Yes, legal action was taken* or *No, legal action was not taken*.

The *Physician Communication* scale (PCOM), a valid and reliable measure originally used by the American Board of Internal Medicine to evaluate patient-provider communication, was used in this study to assess the thoroughness of information provided to the family by the healthcare professional (Heisler, Cole, Weir, Kerr, & Hayward, 2007; Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). The PCOM asks the family member to consider aspects of the healthcare provider's communication of information, specifically: "Telling you everything; not keeping things from you that you should know"; "Letting you know test results when promised"; "Explaining treatment alternatives"; "Explaining side effects of medications"; and "Telling you what to expect from

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treatment" (Heisler et al., 2007). Family members rated these four items by indicating 1 for *Poor*, 2 for *Fair*, 3 for *Good*, 4 for *Very good*, or 5 for *Excellent.* The score range was 4 to 20 with higher scores reflecting better communication.

Information regarding the seriousness of the medical error experience as well as disclosure information was collected using an instrument developed by COPIC Insurance Company and modified for this study (T. Gallagher, personal communication, July, 2008; COPIC, 2004, 2007). Developed for internal review of the effectiveness of COPIC's Recognize, Respond, Resolve (3R's) initiative, the questions and statements in this instrument are primarily used to evaluate a patient or a family member's level of satisfaction with the quality of the disclosure of a medical error occurring in selected Colorado hospitals (T. Gallagher, personal communication, July, 2008; COPIC, 2004, 2007). The first item on the COPIC disclosure instrument establishes a participant's perceived seriousness of the medical error experience. Participants selected an answer to the question, "In your opinion, how serious was the medical error experience?" from four choices: *Extremely serious – died or might have died, Very serious – permanent injury or disability, Somewhat serious – injury or disability that resolved,* or *Not serious at all*. Next, participants indicated the disclosure strategy or strategies put into practice after the medical error experience by selecting *Yes* or *No* to "Provided facts about the medical error", "Apologized for the medical error", "Assurance that steps would be taken to prevent reoccurrence of the medical error'", "Offered to pay costs of associated care" and "Other." This scale is referred to as the "Disclosure Strategies" scale.

In a program guided by data, COPIC actively assists individuals injured by medical error and provides physicians with training in how to put into practice effective disclosure strategies following medical error incidents. To determine satisfaction with the quality of the disclosure, COPIC asks a patient or a family member to rate how closely he or she agrees with statements regarding disclosure. In this study, participants rated thirteen statements by indicating 1 for *Strongly*

Disagree, 2 for *Somewhat Disagree,* 3 for *Neither Agree nor Disagree,* 4 for *Somewhat Agree,* and 5 for *Strongly Agree.* These statements referred to the quality of the disclosure strategies for provision of facts (e.g., "The healthcare professional explained the event using terms I could understand"), apology (e.g., "The healthcare professional provided a sincere apology to me for this event"), assurance of an effort to prevent future errors (e.g., "The healthcare professional assured me that steps would be taken to prevent similar events from happening again"), offering to pay for associated care (e.g., "I am satisfied that the healthcare professional met my out-of-pocket expenses"), and method of delivery of the disclosure (e.g., "The healthcare professional had good listening skills"). The participant's answers to the satisfaction with the quality of the disclosure statements yielded results on a continuous scale ranging from a score of 13 to indicate *Least satisfied* to a score of 65 to indicate *Most satisfied*. This scale is referred to as the "Quality of Disclosure" scale.

Although this disclosure survey is not distributed outside the COPIC program, it has been used within the COPIC 3R's program to evaluate over 2174 medical error incidents since October 2000 (COPIC, 2006). The accumulated evidence provides assurance that the survey reflects the facets of medical error disclosure of interest in this study (T. Gallagher, personal communication, July 2008). Disclosure statements that are not relevant to this study were not included (e.g., "How satisfied were you with the 3Rs administrator's assistance with your case?") and the term "physician" was replaced with "healthcare professional." In addition, the design and layout of the questions and statements were slightly altered to accommodate online assessment.

Trust in the medical profession was assessed using the 5-item *Wake Forest Trust in Medicine* scale (Dugan, Trachtenberg, & Hall, 2005). The measure has acceptable reliability and validity and has been determined to be an adequate measure of a patient's trust in the medical profession (Dugan, Trachtenberg, & Hall, 2005). Responses are scored from 1(*strongly disagree*) to 5

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(*strongly agree*) and summed with higher total scores indicating more trust. Critical to the present study, Dugan, Trachtenberg, and Hall (2005) report that scores indicating lower trust are related to changing doctors, seeking a second opinion, and having had a dispute with a healthcare professional.

Symptoms of trauma were assessed using a modified version of the Detailed Assessment of Posttraumatic Stress (DAPS; Briere, 2001). Based on criteria directly related to the *DSM-IV-TR* (2000; Briere, 2001), the DAPS is a normed, comprehensive, self-report inventory measuring the extent of trauma exposure and the overall severity of the traumatic response in individuals who have encountered a psychological stressor (Plake, Impara, & Spies, 2003).

The 84-item modified DAPS asks a participant to briefly describe a specific traumatic event, which, in this study was the medical error injury incident. Then, using a five-point scale, a participant identified how often a symptom occurred in the last month, with 1 indicating *Never*, 2 indicating *Less than once a week*, 3 indicating *About once a week*, 4 indicating *Two or three times a week*, and 5 indicating *Four or more times a week.* A psychometrically sound measure, the DAPS allows empirical and statistical determination of the severity of PTSD symptoms (Plake et al., 2003) and yields scale subscores for: (a) the cognitive and emotional responses at the time of the medical error injury experience (e.g., "At the worst point, how much fear did you feel during this experience?"; *Peritraumatic Distress* scale); (b) the degree of dissociation at the time of the medical error injury experience (e.g., "Time seemed to slow down or speed up."; *Peritraumatic Dissociation* scale); and each of the three PTSD symptom clusters including (c) reexperiencing (e.g., "Upsetting thoughts or memories of the experience popped into your head."; *Reexperiencing* scale), (d) avoidance (e.g., "Trying not to have any upsetting thoughts or feelings about what happened."; *Avoidance* scale) , and (e) hyperarousal (e.g., "Feeling more restless since it happened."; *Hyperarousal* scale). Trauma specific dissociation found to occur after great trauma

was identified with four items (e.g., "Going around in a daze since the experience, not noticing things."; *Trauma-Specific Dissociation* scale). In addition, a limited review of phenomena sometimes associated with PTSD is included in the DAPS; however, in this study, the DAPS was modified to exclude the supplementary information.

Important to the present study, the DAPS has one item to evaluate how recently the medical error incident occurred and twelve items to establish the cumulative lifetime history of traumatic events (*Relative Trauma Exposure* scale). In addition, the DAPS includes statements that contribute to validity scores assessing underreporting of symptoms that others normally approve (e.g., "Problems in your relationships with people."; *Positive Bias* scale) and overreporting of symptoms that others seldom acknowledge to any significant degree (e.g., "Going blind for several minutes at a time."; *Negative Bias* scale; Briere, 2001). Reflecting good convergent and discriminant validity, the validity scales of the DAPS are significantly correlated with the validity scales from the Personality Assessment Inventory (Morey, 1991), the Trauma Symptom Inventory (Briere, 1995), and the Minnesota Multiphasic Personality Inventory (MMPI-2; Butcher, Dahlstrom, Graham, Tellegen, & Kaemmer, 1989).

Normative *T* score data for the DAPS trauma scales were developed using a sample of over four hundred trauma exposed individuals from the general population (Briere, 2001). This population and the participant population for this study are similar in that they are not groups that are seeking treatment for clinical PTSD. For this reason, an individual's score on a DAPS trauma scale may be compared to the average trauma scale score of a large group of traumatized individuals. A *T* score of 65 or above on any individual DAPS trauma scale reflects significant symptom experience. And, the *Reexperiencing* scale score, the *Avoidance* scale score, and the *Hyperarousal* scale score may be combined to indicate the total extent of PTSD symptoms as reflected in the *Posttraumatic Stress – Total* scale score. The *Posttraumatic Stress – Total* scale

score ranges from 45 to 100 and is used to determine symptom severity with *T* scores less than 60 reflecting a sub-clinical level of symptomatology, *T* scores of 60 to 64 reflecting *Mild* symptomatology, *T* scores of 65 to 74 reflecting *Moderate* symptomatology, and *T* scores of 75 or higher reflecting *Severe* symptomatology (Briere, 2001). Additional categorical results can be determined by using the *Posttraumatic Stress – Total* scale a *T* score less than 60 to indicate no PTSD symptoms and a *T* score of 60 or higher to indicate PTSD symptoms.

Appropriate for use with individuals or groups of individuals 18 years of age and older, the DAPS may be administered by individuals without formal training in clinical psychology (Briere, 2001). And, although the DAPS was developed as a paper and pencil measure, the instrument is available in a computer software program format and has been adapted for online research in other studies (Psychological Assessment Resources, 2008).

Finally, a single open response question ("Briefly describe how life has changed since the medical error incident occurred"; Duclos et al., 2005) was included to gather limited qualitative information about the family members' medical error experience.

In this study, demographic, disclosure, trauma symptom, and qualitative items were combined into a measure referred to as the "questionnaire." Prior to the start of the survey, a pilot survey was undertaken using the questionnaire; 12 individuals participated and provided feedback. Based on this feedback, slight adjustments were made to clarify questionnaire instructions. The questionnaire took approximately 30 minutes to complete.

Procedure

Invitations to participate and study announcements provided information about the aim of the study, the process for gathering data, the web address of the online survey, and a password needed to access the survey. In addition, invitations and announcements included eligibility

requirements and asked that only one member of each family in which a family member has

experienced a medical error should complete the survey. Once a participant logged into the survey

website, information was provided regarding the confidentiality of the information, the right to

withdraw from the assessment, the anticipated risks, and how to contact the researcher.

Participants were provided a consent agreement and indicated consent by selecting "I agree to

these terms" prior to beginning the questionnaire. This method of obtaining consent was approved

by the Committee on the Use of Human Subjects in Research. The online survey was available for

30 days and was closed to additional participants after that deadline.

After indicating consent, participants were asked to use the following definitions of important

terms:

> Disclosure is defined as "honestly telling patients or their families about unexpected harm
> that occurs as a result of treatment or care, not directly because of a patient's illness or
> underlying condition" (Lamb et al., 2003, p. 74).

> Medical error is defined as "failure of a planned action to be completed as intended or the
> use of a wrong plan to achieve an aim" (Rothschild et al., 2005. p. 1695); a "mistake,
> inadvertent occurrence, or unintended event in health care delivery which may or may not
> result in patient injury" (Liang, 2000, p. 543).

Participants were asked to indicate the organization extending the survey invitation, the

participant's relationship to the person injured by medical error, how the participant obtained

information about the medical error, and the health care professional the participant felt most

responsible for the medical error. Next, the participant completed the Physician's Communication

scale (PCOM), the Injury Severity scale, the Disclosure Strategies scale, the Quality of Disclosure

scale, and the Wake Forest Trust scale. Then, participants were given these directions on

completing the slightly modified DAPS:

> Please read all of these instructions carefully before beginning this portion of the
> questionnaire. This is the DAPS questionnaire of trauma exposure and response. You will
> see that the questionnaire sometimes asks you to answer questions about *your thoughts*

and feelings about the medical error experience of a loved one and sometimes it just asks about things in general. Read each of the questions carefully, and then select the one answer that best describes your experience.

This questionnaire contains items describing experiences that may or may not have happened to you. Some of the items ask about your experiences at any time in your life and other items ask about experiences you may have had in the last month. Please read each item as honestly as you can. Be sure to answer every item. You can take as much time as you need to finish. (Psychological Assessment Resources, 2008)

Following the DAPS, participants were asked to respond to the open response question, to provide demographic information (age, gender, race, country, income, and education), and to indicate whether legal action was taken as a result of the medical error. Finally, participants were provided with a debriefing document that included a thank you for participation, a statement about the aim of the study, a list of the research questions addressed in the study, as well as information about the study's importance, the availability of the results, the potential benefits of the research and the researcher's contact information.

To ensure confidentiality, a participant's name and other identifying information was not recorded, included in the data collection process, or attributed to the participant by any combination of demographic information. It was necessary for the internet IP address of the participant to be recorded; however, this information was deleted from the data at the completion of the collection process. No internet tracking techniques (i.e., cookies) were employed and the administrative components of the website were accessible to the researcher via password protected entry only. Survey questions and the survey's online format were approved by the Committee on the Use of Human Subjects in Research at Harvard University.

Quantitative Data Analysis

Data were reviewed to select eligible participants by eliminating submissions that were incomplete, duplicated, or invalid. The scale score for each measure was tabulated

following the rules for that specific scale as outlined previously. Scores for each subscale were reviewed and, to avoid inaccurate inferences and selection bias from listwise deletion (King, Honaker, Joseph, & Scheve, 1998), submissions with less than fifteen percent missing scale scores were imputed: if the missing response informed categorical or nominal data, the largest frequency mode was inserted and if the missing response informed continuous data, the median was inserted. After that, data were tabulated using standard summary statistics (means, standard deviations, frequencies, and percentages). Then, a multiple regression model was developed using the reported disclosure strategies put into practice by healthcare professionals (providing facts about the medical error incident, apologizing for the medical error, making an effort to prevent similar errors from occurring, offering to pay costs of associated care, and other) to predict the severity of reported symptoms of trauma as indicated by the DAPS total score and the DAPS subscale scores. Relevant variables (e.g., gender, time since medical error, participants' perceived severity of the injury) were included as predictors in these regressions. Any variables that were shown to have statistically reliable associations with one or more of the DAPS subscale measures was included, as control variables, in the multiple regression analyses. One-way ANOVA tests were conducted using categorical demographic variables (e.g., gender, race/ethnicity, relation of participant to the patient) to predict reported trauma symptoms (i.e., DAPS subscale scores). Pearson product-moment correlations were conducted to compute the associations between various continuous demographic variables (e.g., age, family income) and reported trauma symptoms. Point-biserial correlation (the Pearson product-moment correlation of a dichotomous variable with a continuous variable) was conducted where appropriate (e.g., litigation and reported trauma symptoms). Next, tests for the three primary hypotheses were conducted.

For the first hypothesis, it was expected that the prevalence of participants reporting trauma symptoms would be similar to that reported in other trauma-exposed populations (see Breslau et al., 1998). Scores on the DAPS *Posttraumatic Stress – Total* scale were used to determine whether or not a participant reported thoughts, feelings and behaviors consistent with symptoms of PTSD (*Yes / No*). Chi-square was used to determine whether this percentage was significantly greater than zero. In addition, a one-sample t-test was used to compare the mean DAPS *Posttraumatic Stress – Total* scale of this population to zero. The prediction was that this score would be significantly greater than zero.

To test the hypothesis that more severe reported trauma symptoms would be negatively associated with an increase in the number of disclosure strategies used by healthcare professionals, the number of reported disclosure strategies (providing facts about the medical error incident, apologizing for the medical error, making an effort to prevent similar errors from occurring, offering to pay costs of associated care, and other) were calculated. This resulted in a score ranging from zero to five. Pearson correlation coefficients were computed to assess the relationship between the number of disclosure strategies and each of the DAPS subscale scores (*Reexperiencing, Avoidance*, and *Hyperarousal*). For all three subscales, a significant negative correlation was expected.

Next, to test the hypothesis that family member's report of more severe trauma symptoms was negatively associated with an increase in the reported quality of the healthcare professional's disclosure, the COPIC quality of the disclosure score was used (scale range from 13 for least satisfied with the quality of disclosure to 65 for most satisfied with the quality of disclosure). Again, Pearson correlation coefficients were computed to assess the relationship between the quality of the disclosure score and each of the three

DAPS subscale scores (*Reexperiencing, Avoidance,* and *Hyperarousal*). It was predicted that greater quality of disclosure would be associated with less severe PTSD symptoms.

The most complex analysis proposed was the multiple regression analysis. The sample size was adequate for an 80% power to detect a moderate size overall effect (R2) with eight predictors. Tests of individual regression coefficients required additional power. Statistical Package for the Social Sciences (SPSS) software was employed in all statistical procedures.

Qualitative Data Analysis

In addition to the quantitative analyses described above, an exploratory qualitative analysis was also feasible. Two open response questions provided descriptions and details of the family members' experiences. Family members typed responses to these requests in the textbox provided on the survey website. Lists of words and phrases were culled from these open-ended responses. These lists were analyzed for recurring themes and key concepts to corroborate or to refute self-report findings. Specifically, the first question asked the participant to describe the medical error experience (DAPS, question 14). The responses to this question were reviewed to identify consistencies, patterns, or progressions that might indicate a common flow of reactions to medical error experiences. The second question asked the participant to describe how life has changed since the medical error incident occurred (Duclos et al., 2005). The responses to this question were reviewed to substantiate findings from the quantitative data. Particular attention was given to descriptions reflecting symptoms of trauma that included thoughts and memories of the medical error experience; conscious attempts to avoid medical people, places, or conversations; tension, sleeping, or irritability problems; and trouble at work, in social situations or in relationships.

The responses were analyzed for evidence of a unifying theme, for information that disconfirms predictions, and for questions that may inform future research.

To reduce the possibility of bias and to increase validity of qualitative findings, an independent review of the qualitative data was obtained. The independent reviewer, a physician with hospital peer review experience, analyzed the qualitative data prior to reviewing the investigator's interpretation of the qualitative data. The independent reviewer was asked to agree with, add to, subtract from, or otherwise alter the analysis. As a result of the independent review, additional categories for concepts were added including "disturbing reports", "failure to listen", "callous comments", "resilience" and "coping."

To protect the identity of the family members, responses to each open response item were randomly assigned alpha-numerical codes. In addition, descriptive terms, identifying relationship labels, and dates were removed.

Chapter III

Results

Results from this retrospective case-controlled study represent a population of individuals that report loved ones harmed by a medical error, an affiliation with a patient safety organization, and a desire to participate in research. One hundred twenty-eight respondents participated in this study.

Quantitative Results

Data was tabulated using standard summary statistics. Table 1 displays demographic characteristics of these family members. The most frequent sources of respondents were CAPS (28.1%), PULSE (18.8%) and the Consumer's Union (18.0%). For 40.6% of the respondents, they were the child of the injured patient. Four of five respondents (80.5%) were female, almost all (94.5%) were Caucasian and all (100.0%) lived in the United States. The ages of the respondents ranged from 25 to 88 years (M= 51.75, SD = 10.42). The respondent's income ranged from "less than $7,500" to "more than $100,000" ($Mdn$ = $62,500). Two-thirds were college graduates (Table 1).

Table 2 displays the frequency counts for selected variables. For about two-thirds of the respondents (65.6%), they wrote that the physician was most responsible for the medical error. For the 91 respondents who rated the seriousness of the medical error, 71.4% reported that the error as "extremely serious." For 32.0% of the respondents, legal action was taken after the medical error (Table 2).

Table 1

Demographic characteristics of family members (N = 128)

Variable	Category	*n*	%
Source of Respondent[a]			
	CAPS	36	28.1
	PULSE	24	18.8
	MITSS	13	10.2
	CU	23	18.0
	Other	32	25.0
Relationship to Patient			
	Spouse	27	21.1
	Parent	31	24.2
	Child	52	40.6
	Close associate [b]	9	7.0
	Other [c]	9	7.0

[a] CAPS: Consumers Advancing Patient Safety; PULSE: Persons United Limiting Substandards and Errors; MITSS: Medically Induced Trauma Support Services; CU: Consumer's Union; Other includes the National Family Caregivers Association (NFCA) and the Agency for Healthcare Research and Quality (AHRQ).

[b] Close associate: 1 grandparent, 1 grandchild, and 7 siblings. [c] Other: 1 cousin, 2 nieces, 1 aunt, 3 healthcare professionals, 1 daughter-in-law, and 1 sister-in-law.

Table 1 c*ontinued*

Variable	Category	*n*	%
Race			
	Other	7	5.5
	Caucasian	121	94.5
Country			
	United States	128	100.0
Age of Study Participant[d]			
	25 to 29 years	5	3.9
	30 to 39 years	12	9.4
	40 to 49 years	30	23.4
	50 to 59 years	62	48.4
	60 to 88 years	19	14.8
Gender			
	Male	25	19.5
	Female	103	80.5

[d] Age: *M* = 51.75, *SD* = 10.42.

Table 1 continued

Variable	Category	*n*	%
Income [e]			
	Less than $7,500	7	5.5
	$7,501 - $15,000	2	1.6
	$15,001 -$25,000	11	8.6
	$25,001 - $35,000	3	2.3
	$35,001 - $50,000	13	10.2
	$50,001 - $75,000	39	30.5
	$75,001 - $100,000	20	15.6
	More than $100,000	33	25.8
Education			
	High school or less	10	7.8
	Some college	32	25.0
	College graduate	86	67.2

[e] Income: *Mdn* = $62,500.

Table 3 displays the item ratings from the *Physicians Communication* scale (Heisler, Cole, Weir, Kerr, & Hayward, 2007) sorted by the highest mean rating. These ratings were given using a five-point scale (1 = *Poor* to 5 = *Excellent*). All five ratings averaged less than three points on the five-point scale with the highest rating being "told you what to expect from your treatment (*M* = 2.32)" (Table 3).

Table 2

Frequency counts for selected variables (N = 128)

Variable	Category	*n*	%
Most Responsible			
	Physician	84	65.6
	Nurse	13	10.2
	System	12	9.4
	Other	19	14.8
Seriousness of Medical Error (n = 91)			
	Somewhat serious	14	15.4
	Very serious	12	13.2
	Extremely serious	65	71.4
Legal Action Taken			
	No	87	68.0
	Yes	41	32.0

Table 4 displays the item frequencies for the *Disclosure Strategies* scale (COPIC, 2004, 2007) sorted by the highest frequency of respondents who answered "yes" to each item. The highest frequency disclosure strategies were "apologized for the medical error (23.4%)," "provided facts about the medical error (17.2%)," and "gave assurance that steps would be taken to prevent reoccurrence of the medical error (14.8%)" (Table 4).

Table 3

Item ratings from Physician's Communication scale sorted by highest mean rating (N = 128)

Physician Communication item	M	SD
Told you what to expect from the treatment	2.32	1.29
Told you everything; not keeping things from you that you should know	2.28	1.31
Let you know test results when promised	2.28	1.20
Explained treatment alternatives	2.20	1.35
Explained side effects of medications	2.00	1.22

Note. Ratings made using five-point scale: 1 = *Poor* to 5 = *Excellent*.

Table 5 displays the psychometric characteristics for the twelve summated scale scores. The Cronbach alpha reliability coefficients for the twelve scales ranged in size from r = .71 to r = .96 with a median coefficient of r = .88. This suggested that all scales possessed adequate levels of internal reliability (Table 5).

Hypothesis One

Hypothesis One predicted that, "that the prevalence of participants reporting trauma symptoms will be similar to that reported in other trauma-exposed populations" (see Breslau et al., 1998). To address this hypothesis, Table 6 displays the results of the chi-square test comparing the *Posttraumatic Stress - Total* score expected score distribution with the actual distribution of

Table 4

Item frequencies for the Disclosure Strategies scale by highest frequency (N = 128)

Disclosure Strategies item	*n*	%
Apologized for the medical error	30	23.4
Provided facts about the medical error	22	17.2
Gave assurance that steps would be taken to prevent reoccurrence of the medical error	19	14.8
Provided counseling or information about emotional support groups	8	6.3
Offered to pay costs of associated care	6	4.7

Note. Frequencies were calculated based on the percentage of respondents who answered "yes."

scores found in this sample.

By definition, a score of 60T is one standard deviation above the mean or the 84th percentile (DeVeaux & Velleman, 2004). Based on that percentage, if this was a non-clinical general population sample then it would be expected that 108 of 128 respondents (84.4%) would have "non-significant" *Posttraumatic Stress - Total* scores when in fact this study had 62.5% of the sample in that category. In the same way, in a general population sample, it would be expected that only 1 of 128 respondents (0.8%) would have "severe PTSD symptoms (75T)" when this sample had 21.1% of the sample in that category. The resulting chi-square value was significant (*p* =.001, Cramer's *V* = .37). This chi-square test provided support for Hypothesis One (Table 6).

Table 5

Psychometric characteristics for summated scale scores (N = 128)

Scale	Number of Items	Critical Score	*M*	*SD*	Low	High	Alpha
Physician Communication	5	3	6.07	5.67	0.00	20.00	.95
Disclosure Strategies	5	2	0.64	1.16	0.00	5.00	.75
Quality of Disclosure	13	3	1.90	0.68	1.00	4.85	.88
Trust in Medicine	5	15	9.88	4.21	5.00	25.00	.84
Relative Trauma Exposure	13	6	2.18	2.14	0.00	10.00	.71
Peritramatic Distress	8	29	30.09	5.95	11.00	40.00	.78
Peritramatic Dissociation	6	18	13.52	6.65	6.00	30.00	.88
Reexperiencing	10	15	22.00	9.12	10.00	49.00	.93
Avoidance	10	20	18.66	8.43	10.00	46.00	.88
Hyperarousal	10	15	19.60	9.00	10.00	46.00	.90
Posttraumatic Stress - Total	30	60	58.31	22.80	30.00	137.00	.96
Posttraumatic Impairment	5	11	10.83	5.81	5.00	25.00	.90

Note: Critical Score ratings reflect scale cutoff scores that indicate good communication, average trust, or probable symptoms

Table 6

Comparison of Posttraumatic Stress - Total scale (PTS-T) score for expected distribution of scores with actual scores from family members (N = 128)

Clinical Category	T Score	Percentiles	Expected Distribution		Actual Distribution	
			n	%	n	%
Non-significant	Less than 60	Under 84	108	84.0	80	62.5
Mild symptoms	60 to 64	84 to 93	13	10.0	6	4.7
Moderate symptoms	65 to 74	94 to 98	6	5.0	15	11.7
Severe symptoms	75 and higher	99 and higher	1	1.0	27	21.1

Note. Expected distribution was calculated based on interpretation of *T* scores.

X^2 (3, *N* = 256) = 34.75, *p* = .001. Cramer's *V* = .37.

Hypothesis Two

Hypothesis Two predicted that, "more severe reported trauma symptoms will be negatively associated with an increase in the reported number of strategies used by healthcare professionals." To address this hypothesis, Table 7 displays the results of the Pearson product-moment correlations for the number of disclosure strategies with the seven measures of trauma

symptoms. The number of disclosure strategies was negatively related to the *Posttraumatic Stress*

- Total scale (r = -.18, p < .05) and the *Posttraumatic Impairment* scale (r = -.20, p < .05) (Table 7).

Given that only two of the seven trauma symptom measures were significantly related to the

number of disclosure strategies, these findings provided limited support for Hypothesis Two.

Hypothesis Three

Hypothesis Three predicted that, "family member report of more severe trauma symptoms

will be negatively associated with an increase in the reported quality of the healthcare

professional's disclosure." To address this hypothesis, Table 7 displays the results of the Pearson

product-moment correlations for the Q*uality of the Disclosure* scale (COPIC, 2004, 2007) with the

seven measures of trauma symptoms. All seven correlations resulted in significant, negative

coefficients with the largest correlations being with H*yperarousal* (r = -.32, p < .001), *Posttraumatic*

Impairment (r = -.31, p < .001), and *Reexperiencing* (r = -.30, p < .001) (Table 7). These findings

provided support for Hypothesis Three.

Additional Findings

Cohen (1988) suggested some guidelines for interpreting the strength of linear correlations.

He suggested that a "weak correlation" typically had an absolute value of r = .10 (about one

percent of the variance explained), a "moderate correlation" typically had an absolute value of

 r = .30 (about nine percent of the variance explained) and a "strong correlation" typically had an

absolute value of r = .50 (about 25 percent of the variance explained). Therefore, for the sake of

parsimony, this Results Chapter will primarily highlight those correlations that were at least

"moderate strength" to minimize the potential of numerous Type I errors stemming from interpreting

and drawing conclusions based on potentially spurious correlations,

Also in Table 7 are the correlations for the *Physician Communication* scale (Heisler, Cole,

Table 7

Correlations for trauma symptom scales with Physicians Communication, Disclosure Strategies,

Quality of Disclosure, and Trust scales (N = 128)

Trauma Symptom Scales	Scales [a]			
	One	Two	Three	Four
Peritramatic Distress	-.16	-.10	-.26 ***	-.20 *
Peritramatic Dissociation	-.24 **	-.12	-.24 ***	-.22 *
Reexperiencing	-.25 ***	-.13	-.30 ****	-.22 **
Avoidance	-.20 *	-.16	-.24 **	-.20 *
Hyperarousal	-.30 ****	-.17	-.32 ****	-.22 **
Posttraumatic Stress - Total	-.25 ***	-.18 *	-.29 ****	-.21 *
Posttraumatic Impairment	-.27 ***	-.20 *	-.31 ****	-.20 *

[a] Scales: One = *Physician Communication*; Two = *Disclosure Strategies*; Three = *Quality of Disclosure*; Four = *Trust in Medicine*.

* *p* < .05. ** *p* < .01. *** *p* < .005. **** *p* < .001.

Weir, Kerr, & Hayward, 2007) and the *Trust in Medicine* scale (Dugan, Trachtenberg, & Hall, 2005)

with the seven measures of trauma symptoms. The quality of the physician's communication was

negatively related to six of seven trauma symptom scales with the largest correlation being with *Hyperarousal* (r = -.30, p < .001). Trust in medicine was also significantly related to all seven measures of trauma at the p < .05 level but none was of moderate strength using the Cohen (1988) criteria (Table 7).

Table 8 displays the Pearson product-moment correlations for 12 summated scale scores with six demographic variables. For the resulting 72 correlations, 33 were statistically significant at the p < .05 level and eight were of "moderate strength" based on the Cohen (1988) criteria. Specifically, the reported level of the severity of medical error was positively related to *Peritraumatic Distress* (r = .35, p < .001), *Peritraumatic Dissociation* (r = .35, p < .001), *Reexperiencing* (r = .34, p < .001), and the *Posttraumatic Stress - Total* score (r = .30, p < .001). The respondent's level of education was negatively related to *Peritraumatic Distress* (r = -.32, p < .001), *Peritraumatic Dissociation* (r = -.37, p < .001), and *Posttraumatic Impairment* (r = -.32, p < .001). In addition, whether legal action was taken was positively related to *Peritraumatic Distress* (r = .30, p < .001) (Table 8).

Table 9 displays the results of the backwards elimination regression model predicting the respondent's total PTSD score based on ten candidate variables (four measures of the medical relationship - *Physicians Communication, Disclosure Strategies, Quality of Disclosure, Trust in Medicine* – and six demographic variables). The final four-variable was significant (p = .001) and accounted for 16.4% of the variance in the respondent's *Posttraumatic Stress - Total* score. Inspection of the beta weights found that the respondent's *Posttraumatic Stress - Total* score was higher for: (a) lower *Quality of Disclosure* scores (β = -.24, p = .006); (b) females (β = .16, p = .06); (c) respondent's with less education (β = -.19, p = .03); and (d) respondents whose families took legal action (β = .16, p = .07) (Table 9).

For Table 8

Correlations for scale scores with selected demographic variables (N = 128)

Scale Score	Age	Seriousness of Injury [a]	Gender [b]
Physician Communication	.10	-.18	-.07
Disclosure Strategies	-.18 *	-.01	.02
Quality of Disclosure	.04	-.10	-.03
Trust in Medicine	.06	-.17	.02
Relative Trauma Exposure	-.04	.11	.05
Peritramatic Distress	-.22 **	.35 ****	.12
Peritramatic Dissociation	-.22 **	.35 ****	.10
Reexperiencing	-.21 *	.34 ****	.12
Avoidance	-.13	.25 *	.12
Hyperarousal	-.13	.25 *	.22 **
Posttraumatic Stress - Total	-.13	.30 ***	.16
Posttraumatic Impairment	-.17 *	.18	.09

[a] Correlations were calculated for the 91 respondents who answered the question.

[b] Gender: 1 = *Male* 2 = *Female*.

 * *p* < .05. ** *p* < .01. *** *p* < .005. **** *p* < .001.

Table 8 c*ontinues*

Table 8 c*ontinued*

Scale Score	Income		Education		Legal Action Taken [c]	
Physician Communication	.15		.18	*	-.14	
Disclosure Strategies	.06		.08		.14	
Quality of Disclosure	.15		.17	*	-.07	
Trust in Medicine	.05		.06		-.09	
Relative Trauma Exposure	-.13		-.14		-.09	
Peritramatic Distress	-.16		-.32	****	.30	****
Peritramatic Dissociation	-.17	*	-.37	****	.25	***
Reexperiencing	-.16		-.29	****	.24	**
Avoidance	-.24	**	-.19	*	.21	*
Hyperarousal	-.23	**	-.24	**	.20	*
Posttraumatic Stress - Total	-.20	*	-.24	**	.18	*
Posttraumatic Impairment	-.31	****	-.32	****	.18	*

[c] Legal Action: 0 = *No* 1 = *Yes.*

* *p* < .05. ** *p* < .01. *** *p* < .005. **** *p* < .001.

Table 9

Prediction of Total PTSD score based on selected variables. Backward Elimination Regression

(N = 128)

Variable	*B*	*SE*	β	*p*
Intercept	79.50	9.55		.001
Quality of Disclosure	-7.90	2.84	-.24	.006
Gender [a]	8.85	4.75	.16	.06
Education	-6.22	2.82	-.19	.03
Legal Action Taken [b]	7.56	4.06	.16	.07

Note. Final Model: $F (4, 121) = 5.92$, $p = .001$. $R^2 = .164$. Candidate variables = 10.

[a] Gender: 1 = *Male* 2 = *Female*.

[b] Legal Action: 0 = *No* 1 = *Yes*

Qualitative Results

The qualitative data allowed an in-depth review of family members' response to the medical error injury of a loved one. First, detailed accounts of the medical error injury from the family members' perspective are presented. These accounts are followed by descriptions of family members' life following the medical error experience.

Family Members Report of Medical Error

These family members responded to the DAPS open response item, "Briefly describe the medical error experience" using the definition of medical error provided in the introduction to the survey. The family members described how they witnessed medical care of a loved one, or acquired medical records documenting the loved one's medical care, or obtained expert opinion about the loved one's medical care. In addition, some family members stated that information about medical care was withheld from them or that requests for explanations for medical care events were not honored. The family members' descriptions of medical error experiences given in answer to the DAPS open response item were evaluated and organized as previously detailed. Selected responses follow.

Some family members in this group described medical experiences where "a failure of a planned action to be completed as intended" occurred (Rothschild et al., 2005. p. 1695). For example, one family member reported "the surgeon committed surgical errors and conducted a different operation than was consented" (Family Member [FM] 52). In another reported medical error experience, a patient did not receive treatment for cancer. The family member explained,

> The plan was to also include chemotherapy but the MD responsible for his care did not follow through on the treatment nor did my [loved one] know it was part of the treatment plan so he never asked. I learned of the omission when I read his chart. (FM 79)

One family member reported that antibiotic treatment was delayed for a parent, "My mother was admitted to [the] hospital for elective surgery and developed surgical infection/MRSA with which she became septic and died in the hospital. Antibiotics were ordered but not started on time and one not at all" (FM 408).

Respondents described the use of wrong plans in the delivery of medical care in addition to plans that failed to be completed as intended. In this study, experiences that described the "use of a wrong plan to achieve an aim" (Rothschild et al., 2005. p. 1695) were considered medical error.

Some of the experiences identified as wrong plans involved medications. For example, one respondent gave an account of the administration of a drug to an elderly patient that was recovering from a stroke and pneumonia (FM 45). The medication had a black box warning that the drug causes cardiac arrest and pneumonia in elderly individuals. According to the family member, "About 5 days later, [the loved one] was recovered from the pneumonia and scheduled to return to rehab…and suddenly died." The respondent continued, "It is clear to me that the drug given is the cause…."(FM 45). Another respondent also described the use of a drug "off-label" to induce labor. The family member stated, "My [baby] was deprived of oxygen for over 20 minutes prior to birth due to the effects of cytotec….The birthing staff and MD did not tell me the drug was being used in an off-label use" (FM 117).

In addition to the medication errors that family members' reported as wrong plans, several family members reported the mistaken administration of medication. The survey definition of medical error included mistakes that resulted in injury (Liang, 2000, p. 543). The mistakes also included procedural errors, surgical errors, or diagnostic test errors.

Examples of medication errors reported by respondents included the administration of pain medication without consent (FM 199); "a 5x overdose of morphine" (FM 18); the administration of tnK instead of Tpa that resulted in a "brain bleed" and death (FM 110); the "…double dose of Baclofen to someone who was already incontinent and weak" (FM 122); and an overdose of insulin given to a diabetic patient (FM 250). One respondent reported a medication error as part of a series of mistakes that resulted in the death of a loved one. The family member stated, "My [loved one] was given a high dose of anti-anxiety medicine along with a high dosage of pain killer to tolerate a needed MRI on his back" (FM 397). The family member explained why the administration of the medication was a mistake, "He had pulmonary problems and never should have been given this combination." Unfortunately, the medication error was not the only mistake. The family

member wrote, "Further to the high drug does [*sic*] he was transported to the MRI facility without his oxygen and was without it for the duration of the MRI. He was brought back to the hospital which ordered the MRI purple in color and went into respiratory arrest." The injury to the patient was described:

> He was intubated, and when he came off of the ventilator 3 days later he was not the same person. It took me digging through his medical records to figure out what had happened to him. Basically, he was deprived of oxygen that killed his brain cells and he became psychotic….He died after a 40+ day hospitalization. (FM 397)

Procedural error that resulted in injury was noted by family members in other reports. One mother said, "My [baby] had one of his small toes amputated in the NICU while a nurse was trying to remove the tape that had held an IV line in place" (FM 119). Another family member described a procedural error that occurred during a sibling's induced labor, "They overdosed her with an epidural causing her and her child to go into cardiac arrest. They did not give her any vasopressions to start her heart again until ten minutes later" (FM 139). The family member explained the seriousness of the injury, "Now she has permanent brain injury and is unable to take care of herself or her child" (FM 139). Another respondent described a procedural error that injured an adolescent child. The family member stated, "The anesthesiologist failed to take a cap off an esophageal pacer wire before inserting it down the esophagus. The cap then gouged my [child's] esophagus and caused a lot of bleeding, which in turn caused [the child] to get a blood transfusion" (FM 241).

Accounts of surgical errors were reported more frequently than procedural errors. Descriptions of randomly selected surgical mistakes are presented here.

> Spouse's intestine was perforated during an ERCP pre-cut outpatient procedure, resulting in necrotizing pancreatitis and septicemia, surgical ICU admission, multiple surgeries, insertion of multiple drains over 10 months, and recovery taking more than 18 months. (FM 97)

During the operation, there was evidently a miscount, and there was a [pad] left in my wife's abdomen. The situation was not revealed until a suspicious gynecologist requested a cat scan. The condition was confirmed by our internist. Subsequently, another surgeon removed the pad successfully. (FM 145)

My [loved one] had the bilater [*sic*] bidirectional Glenn heart surgery when he was 3 months old. We found out when he was almost 2 1/2 years old that the surgeon connected one of his superior vana [*sic*] cava (he has 2) to his pulmonary vein instead of his pulmonary artery. This has caused his oxygen sats [*sic*] to be in the 80's all the time. He has to have [another] heart surgery to fix this mistake. (FM 257)

… she walked into the hospital for elective surgery, 6 hours latter [*sic*] she was a "Quad", and all the surgeon said was "ah, she was gona [*sic*] be a quad anyway". I found out from the records she never had pre-op sep/mep studies done, the Intraoperative monitoring told the surgeon of danger befo [*sic*] the first cut was ever made, The head surgeon was 3 hours late for the 4 hour surgery. (FM 67)

My [loved one] was to have her left kidney removed, due to nephrosis. The surgeon cut her vena cava, mesenteric artery and another artery. The vascular surgeon that was called in said there appeared to be no problem and left. 90 minutes later he was called in again and tried to repair the divided vein and artery. She was returned to ICU in critical condition. 24 hrs later they reopened her and removed her spleen, other kidney, 90% of colon and section of small intestine, gallbladder and probably other organs, I forget. She was returned to ICU with brain death. (FM 277)

Descriptions of mistakes that occurred during diagnostic testing or found in diagnostic test reports were given by family members. Some reports did not provide detailed information. For example, one respondent's complete report stated, "patient was discharged with critical lab values and died" (FM 12). Other reports of mistakes related to diagnostic tests were more elaborate as shown in a respondent's explanation of test findings that were not addressed in the test report. The family member wrote, "After presenting at ER with symptoms consistent with an aneurysm, the Neurologist read an MRI that showed a possible aneurysm but did not indicate the result was abnormal" (FM 55). The family member explained the consequences of the mistake, "When symptoms returned (indicating bleeding), the nursing staff ignored them and refused to take action or obtain treatment until it actually ruptured and patient had to be on life support." The report

continued, "Subsequent treatment failed (neuro coiling) and patient ultimately died" (FM 55). One respondent's spouse endured a series of unnecessary procedures because of a mistake in interpretation of diagnostic test information. The family member described how the ordeal began, "The cardiologist read the echocardiogram as showing something that might be a clot in his inferior vena cava" (FM 112). The introductory information was followed by the family member's description of the CT scan experience that included a careful explanation of the "gating of the CT slices" and the difference in a contrast with a "venous push" and an "arterial push." The family member's account continued,

> On the recommendation of the primary care physician, my spouse underwent an inferior vena cavagram--an interventional procedure requiring informed consent, discomfort and risks to see whether there was a clot. Lo and behold--there was no clot! We were told that the "clot" was just "an artifact" on the echocardiogram. (FM 112)

The family member summarized the ordeal, "Thus, an improperly read echocardiogram led to an unnecessary, and improperly performed, CT scan with contrast, which led to an unnecessary inferior vena cavagram." The family member concluded, "Although the primary care physician expressed his concern, I don't think that the cardiologist even knows that he misread the echo" (FM 112).

Several descriptions of medical error experiences involved multiple mistakes. A respondent's account of delayed treatment is an example. The respondent wrote, "Family member admitted, continued in severe resp [*sic*] distress & pain throughout the night. When family questioned why symptoms continued, House MD said Dx was pneumonia, ICU nurse said she had other patients who needed her attention more" (FM 63). According to the respondent, "the following morning the family was told that the patient had "a 'blown' mitral value and needed transfer to medical center immediately." After the family requested a particular medical facility the "cardiologist said there was not time to get patient to family's choice 25 miles away." The respondent noted, "This was at 8:30

a.m. At 6 p.m. patient was still in original hospital, transport unit never came. When family

questioned nurse, they were told that they were waiting for a bed at medical center." The

respondent explained how the family rescued the patient:

> Family attempted to call cardiologist numerous times during the day without a response.
> Family contacted another cardiolgist [*sic*] who had privileges at the receiving medical
> center and arranged for immediate transfer. When transferred, patient was immediately
> intubated and prepped for replacement valve surgery. (FM 63)

An explanation for the mistake was sought, "Family questioned admitting hospital administrator

regarding the delay and was told that the regular cardiologist had office hours all day and

'assumed' that the transfer had taken place" (FM 63).

Another respondent described a series of mistakes that occurred after a loved one completed

a routine colonoscopy and "went into the hospital to have a benign polyp removed" (FM 155). The

family member explained, "During the procedure, his gallbladder was nicked and his bowel later

became ischemic. While in the hospital waiting for his bowels to return to normal, he suffered from

toxemia and then suffered a pulmonary embolism." According to the family member, the situation

worsened, "While being intubated following the embolism, his dentures were left in and became

lodged in the back of his throat. They remained there, undetected, for the next 10 days." The

consequences of the ordeal were incredible, as the family member recounted,

> He spent a total of 46 days in ICU, most in a medical coma.   He wound up having his gall
> bladder removed, and a colostomy, during a second surgery. The second surgery was
> performed by a different surgeon -- after a GREAT deal of struggle we had the first
> surgeon removed from the case. He has since had two additional surgeries -- one to
> reverse the colostomy and one to repair a hernia. (FM 155)

The following example of multiple mistakes occurring in the delivery of medical care concerns a

patient that sought care for flu-like symptoms:

> My friend contracted the flu and became dehydrated; went to primary care physician and
> was immediately directed to go to local medical center; was seen by nursing staff and
> diagnosed as dehydrated; given intravenous fluids; when his condition didn't improve he
> tried to check himself out and was dosed with 5 ambien and other sedatives to calm him

down; after being so dosed he went into cardiac arrest but wasn't discovered immediately (discovered on rounds); was brought back but never regained consciousness; vital systems started shutting down (kidneys, liver, etc.); went into full myocardial infarction and died. The attending doctor never came in to check on him until after the first heart attack - all prescribing done over the phone. Once attending physician came in he said that causal symptom was sepsis. (FM 407)

In addition to mistakes that resulted in injury, "inadvertent occurrences or unintended events in health care delivery" (Liang, 2000, p. 543) that resulted in patient injury were part of the survey definition of medical error. The following example of an unintended event was given by a respondent, "My [loved one] was left alone in a wheelchair. He attempted to get up on his own, fell injuring his head and subsequently died from the head injury" (FM 159). A heart wrenching example of an unintended injury was submitted by the mother of an infant. The mother began by explaining that the nurse was not comfortable feeding the infant "with a TP feeding tube" so the nurse "insert[ed] an NG tube" (FM 180). The mother continued, "I did tell her about the difficulty the staff had earlier in the week putting an NG tube in his nose. She struggled and then got it in." The nurse fed the infant; however, the infant developed problems. The mother wrote:

> He seemed to be very fussy that day, and later I paged the nurse because he was sounding raspy and was blowing whitish bubbles out of his mouth. We were concerned about his condition, but the nurse did not call the physician and a chest x-ray was not ordered. (FM 180)

During the day several nurses suctioned the infant and slight improvement was noted. Still, other family members expressed concern. The mother continued:

> [Other family members] told the evening nurse that he appeared to be pale and slightly blue. She told them that 'he is just having trouble getting it together and he gets overwrought.' She then repositioned him in his bed and his color started to slighty [sic] improve. (FM 180)

According the mother, the slight improvements did not last, "he started blowing whitish bubbles and made gurgling sounds and his color was off, so we paged the nurse. The nurse came in and we told her about his gurgling and blowing whitish bubbles." Another suctioning procedure

followed by another feeding made the condition worse. Finally, the mother wrote that her baby, "…suffered cardiac arrest in front of our eyes and died. There was an autopsy done, which held that the cause of death was cardiac arrest, secondary to respiratory arrest, secondary to misplacement of an NG tube in the trachea" (FM 180).

Complications of illness that were preventable or were inappropriately responded to by healthcare professionals were described by some family members. For example, a respondent reported that a loved one complained of bloating, itching, and an inability to void prior to surgery. The respondent wrote, "Went to surgery for lithotripsy- coded on table, ended up on vent- could have been avoided if health care professionals listened to patient and family that something wasn't right" (FM 17). Further descriptions of the experience revealed that the patient was experiencing an allergic reaction to medications and that it "was Friday afternoon and [the] physician was overheard saying 'let's get this done- quick and easy' " (FM 17). In another example, a parent recognized signs of a known complication to illness; however, medical professionals did not respond to the parent or to the evidence of complications. The parent explained, "[Child] with meningitis displayed multiple warning signs of developing cerebral edema. I could not persuade treaters that Cheyne Stokes respirations and MRI evidence of cerebellar substance in spinal canal warned of cerebral edema. Treaters failed to consider abnormal findings in context of diagnosis" (FM 54).

 Experiences that were considered medical error that did not result in injury (Liang, 2000, p. 543) were noted by family members. Accounts of these non-injury experiences included medication errors (FM 79; FM 134; FM 143); a spouse's report of her husband having blood drawn and blood pressure taken in the arm that had "a life threatening blood clot" and being fed too quickly in a feeding tube (FM 123).

Some descriptions of events considered by family members to be medical error portrayed less than careful care. For example, a family member experienced a difficult time trying to get medical

45

help for a loved one:

> [The loved one] died from a punctured coronary artery from misplaced heart stents. I begged for a doctor for an hour and 20 minutes, around the nurses desk. The doctor on call was called immediately and waited an hour and 20 minutes to come to the hospital to a zero BP patient. In his depositions, he stated he did not feel that it was important enough to come at that time. (FM 256)

In addition, callous comments were noted by some respondents including one report of a physician that said, "everything has been done for your mom, her care has cost over a million dollars....imagine if everyone utilized those resources....our society could never bear that" (FM 216). Respondents indicated that insensitive remarks made by healthcare providers were difficult to address. For example, a family member tried to remind a physician of the steps that needed to be taken during a procedure. The family member noted, "I cautioned him that she had Factor V Leiden and needed to be heparinized" (FM 109). The family member stated that the physician asked, "when did you get YOUR medical degree?" In response to the question, the family member began to outline the patient's long history of serious complications related to this condition. Unfortunately, the family member stopped because the patient felt uncomfortable. The family member stated, "My [loved one] did 'not want a fuss, the Doctor would know what had to be done.' Bottom line, my [loved one] died of massive stroke 2 days later" (FM 109).

While some reported medical error experiences reflected carelessness, several reported medical error experiences revealed inappropriate responses from healthcare professionals. Disturbing details of the inappropriate response of healthcare providers to the reported medical error were included in the family members' descriptions of the experience. These troubling reports described responses that family members identified as abandonment, cover up, deception, and fraud.

Respondents described experiences where physicians abandoned the patient. For example, one respondent reported that a loved one's bad response to chemotherapy resulted in a physician

being no longer willing to treat the patient (FM 296) and another respondent reported that a patient

suffering from cancer was refused all care after not consenting to surgery, radiation, or

chemotherapy (FM 121). Respondents described experiences where medical errors were hidden

by healthcare professionals including a family member's report of records being changed when a

physician prescribed a "high dosage of birth control pills" that resulted in the patient suffering a

debilitating stroke (FM 345) and a family member's report of a child that "died as a result of his

cardiologists' failure to treat his extreme potassium depletion" (FM 45). In the second example, the

child's parent explained, "It was those false entries that first alerted me that his care was full of

mistakes" (FM 45). Respondents described experiences that included deception as noted here:

> The technician responsible for my [loved one's] hearing aids was found to be pretending to
> do her job. For four years, she was supposed to be adjusting my [loved one's] hearing aids
> and/or helping her to acquire new ones. She ignored the results of tests and just told my
> [loved one] to continue with the hearing aids she had. One day, my [loved one] went for
> her hearing exam and asked where her technician of four years was, and was told she had
> been terminated. An explanation was not provided, and no one said anything to my [loved
> one]. Following her hearing exam, she was given new hearing aids and she has regained
> a significant portion of her hearing. (FM 163)

The troubling accounts of abandonment, cover up, deception, and fraud were overshadowed by

the descriptions of experiences involving poor communication – especially the failure of a

healthcare professional to listen to the patient or the family member. In fact, family members were

candid about how emotionally difficult the medical error experience was when healthcare providers

did not listen to or respond to obvious symptoms, specific information, or requests made by the

patient or the patient's family. In this study, failure to listen to the patient or family member, failure

to respond to information provided by the patient or family member, and failure to provide the

patient or family member with helpful information was commonly reported (Table 10).

The following description of a respondent's medical error experience highlights the problem

and documents the frustration reported by most respondents. A family member suspected a mix-

Table 10

Words family members used to describe healthcare professional's failure to listen

begged for a doctor, cautioned him;

nursing staff ignored them;

despite my leaving notes for the doctor he would not provide the blood thinners;

mix up could have been corrected had there been someone willing to listen;

I could not persuade treaters;

repeatedly asked that she be seen;

I started telling them something was wrong with my daughter and continued throughout the night;

could have been avoided if health care professionals listened;

we complained to the surgeon and hospital personnel that something was seriously wrong, they

ignored our complaints;

We put up signs in her room that she was allergic to heparin and penicillin, it was even put inside

her chart and on the outside of her chart. The nurses would take the signs down;

endured that damage until I found a doctor/surgeon who believed that the chronic pain "was not in

my head" and surgically intervened

up of blood samples taken in the ER after a [loved one] seeking care for chest pains was given

liver disease test results (FM 128). The family member wrote, "I questioned the tests and asked to

see the results & her chart. He told me he was busy." Then, the family member overheard the

doctor tell the patient in the next room that he was being admitted for a heart attack. The family

member stated, "A red flag went off [and] I suspected that the tech taking the samples had mixed

them up - either at the time of draw or in the lab." At that point, the family member took action, "Although I attempted to get the attention of someone in ER - no one would listen to me. I checked my [loved one] out AMA and drove her (as fast as I could) to the medical center we usually would have gone to." The family member continued, "It turns out that my [loved one] did have a heart attack, was admitted and subsequently had bypass surgery….Had I not questioned what I was told and taken her to another ER she would have most likely died." This respondent explained how prior experience with medical care situations informed the decision to take action. The family member wrote, "I am familiar with hospitals and ER's - my father was a physican [*sic*] and taught us to use our brains not to blindly accept. I understand that errors happen and having an [*sic*] family member advocate in an emergency situation is important" (FM 128). Finally, the family member summed up the entire experience by stating, "The true error was that no one listened."

Many responses to the question, "Briefly describe the medical error experience" included descriptions of the family members' emotional reaction. Table 11 lists some of the words and phrases family members used to describe their feelings at the time of the medical error event.

How Life Changed After the Medical Error Experience

It was possible to learn about life following the medical error injury of a loved one by asking family members to "Briefly describe how life has changed since the medical error experience." In response to this request, family members in this group described suffering that ranged from mild lingering anxiety to symptoms of distress that interfered with all aspects of functioning. Several themes emerged from the data and are presented here.

Some family members are overwhelmed with the changes that followed a medical error experience. One family member described intense feelings of distress following the death of a parent:

Table 11

Words family members used to describe their reaction to the medical error
shame and guilt that I did not know;
scarred for life;
shocked beyond belief;
lost;
helpless;
was so devastating you can not imagine;
rocked to the core;
we all failed;
let down by the very system that was put in place to protect;
there is no future;
I ran into the hall and hollered;
no one standing with me;
helpless against the outside hospital;
I lost everything;
deep despair;
no one understands;
changed;
the experience was horrible;

Table 11 c*ontinued*

Words family members used to describe their reaction to the medical error
traumatized emotionally;
a forever feeling of dread that this will never be over;
I begged them;
extreme guilt;
terrified;
devastated;
I knew they were messing up and was helpless;
completely traumatized;
betrayed;
totally distraught;
it was so quick and unexpected;
shaken;
life altering;
a very horrific experience;
was not expected;
powerless;
especially difficult;

Table 11 c*ontinued*

Words family members used to describe their reaction to the medical error
we are living in a holocaust;
emptiness;
life was destroyed;
very alone;
I cried;
felt like we were in the twilight zone;
sheer torture;
mistreated;
I really wanted to hit her, but did not, as I don't hit people - but it was VERY TEMPTING!!! [*sic*]

> My life is empty. My family is shattered. My sister blames my dad and me for not
> encouraging mom to get a 2nd opinion. I have not talked (nor has my dad) with my sister
> in the past year.....she left the day after the funeral. (FM87)

This family member also copes with the remaining parent's devastating loss, "My dad is in horrible

grief, stuck in grief. He has gained over 40 lbs and now has diabetes. I now take care of my dad

because of his declining health, he suffers from depression and won't seek treatment." Clearly, the

ordeal has taken a toll:

> My marriage suffered enormously, I've no time for friends, I basically have no life left. I
> give everything to care for others and have nothing left to draw from for my own self care.
> I've put myself last, because, I need to care for father, husband, grandson first. My work is
> no source of joy, there really is no joy in my life anymore. My mother was killed. (FM 87)

The family member explained how a lack of support adds to the distress, "… and I have no support emotionally. No one from the medical community has come forth to take accountability and make whole (how can you make a death whole again?) what we've lost." This family member struggles to move forward, "There will never be closure........all because a doctor is [more] worried about his career than the fact that he needs to come to terms and be held accountable for my mother's death?" (FM 87). Many family members noted similar emotional responses lasting for long periods of time. Family members commonly reported that thoughts of the medical error experience or memories of the loved one caused bad feelings. Table 12 lists some of the words family members used to describe painful memories.

Intrusive memories can be difficult to avoid and may contribute to a lack of trust in medicine. As one family member noted, "I am extremely distrustful of the medical profession and experience constant nightmares about the situation going worse and how my [loved one] looked and felt as she was taken away" (FM59). In addition to traumatic memories, some family members report feelings of fear or distress when they or others are in need of medical care. Consequently, some family members report that medical care decisions can be difficult following a medical error experience. One family member explained, "We are trapped in a medical nightmare, all future medical procedures and/or recommendations are weighed by this experience" (FM 94). Table 13 lists words and phrases family members used to describe feelings about medical care.

In spite of the anxiety, the need for medical care is ever-present – especially when a loved one is chronically ill. In some situations, family must cope with the problem of seeking additional medical care from the providers that previously caused harm. Some family members report engaging in extensive illness research, conducting background searches of the healthcare provider, or seeking medical care from providers in distant places as way to tackle care-seeking distress. Many family members connect the fear of medical care with a reduced trust in healthcare

Table 12

Words family members used to describe traumatic memories
I feel like I was robbed of the ability to think of him the way I want;
I cry all the time;
find myself sometimes now just not wanting to think about it, yet I Think of her;
I have to live with that every day because I didn't do more to help her;
it NEVER [*sic*] goes away;
I am sitting here typing tearing up;
I still have flashbacks;
as much as I would like this to all go away it never leaves me;
I am sick thinking again how this was allowed to happen;
will it ever get better;
I can't think about him without that fact crossing my mind;
had terrible nightmares;
hurt and sad every time I have to see my relative;
angry, have nightmares;
every day I remember what happened to my dad, EVERYDAY [*sic*];
you're always thinking about it;
constant nightmares about the situation going worse
trauma of remembering the need of a double surgery remains with us as a horrific (though fading) memory;

Table 13

Words family members used to describe feelings when medical care is needed
I sometimes cry when going to or leaving doctor's appointments; any experience with the medical field causes anxiety; the anxiety of just going to them is too much; vowed to never go back to the same hospital again; extreme unease regarding potential medical mistakes; I have a fear of going to the hospital; I am terrified of getting sick; It frightens me that so many older people without family have no one to be their advocate at the times they are most frail and vulnerable; I fear constantly that this or some similar occurance [*sic*] will once again place me at the mercy of some inept so called physician; Fear for anyone I care about going to see a Dr. Pure terror if they are going to the hospital. Fear they will not return;

professionals:

> My [loved one] continues to have problems related to the diagnosis. I, myself, now live with fear that she may become more ill or pass away due to the incompetence she [experienced] when getting treatment. I never had this fear, or any similar fears, before the incident. I also trust medical professional less than I did before. (FM 91)

Supporting the fear and reduced trust association, a family member stated, "I fear needing a medical professional in the future and being able to trust them" (FM 36). And one family member

explained how fear and distrust would shape future medical relationships, "I pity any nurse that has to deal with me medically in a hospital in the future because I will be watching them ever so closely and not trusting them at all" (FM 180). Table 14 lists actions family members report taking when medical care is needed.

Telling the story of their medical error experience is the way one family member deals with feelings of fear and distrust:

> I continue to live in fear of the day me or my family ever has to go to a hospital again. I myself haven't been to a physician since [date removed], I don't trust anything about the healthcare system and the only way I know to improve it is to continue to tell our story. (FM 87)

Retreating from life in general was reported by some family members. For example, a family member wrote, "My husband has noticed a big change, I am not as engaged in life any more" (FM 80). Similarly, another family member stated, "I am not as passionate about things as I used to be; I would describe it as a sense of feeling 'dulled'....like I lack enthusiasm for things that used to instill passion in me" (FM 66). For one family member, the change they have experienced interferes with the ability to function, "I am very unorganized; I'm tired, lazy, angry, confused, worried; my life will never be the same; I'll never feel true happiness no matter how much I try" (FM 124). And one family member explained, "I wish I could just disappear where no one knows who I am or the hell I live with" (FM 6).

In contrast to the family members reporting a general numbing of emotions, some family members report remarkably powerful emotional reactions that provoke an intractable desire to take action. Consider the response of one family member to the sight of the hospital where the medical error occurred:

> I have to drive by their facility 1x per week- and I want to go the doors and tell the hospital patients to get out of there- they will be killed- and I want to scream and yell at them and I want to picket at their facility. (FM10)

Table14

Words family members use to describe actions taken when confronted with a medical situation

I tell everyone when you go to the ER have two people with you;

I put it off as long as I can; I do not go to all those annual tests;

NEVER leave the person your there with. Even to go to the bathroom;

I am more vigilant about getting good quality care;

not going to the doctor for any treatment even if I need to;

I feel that I have to be there almost 24/7 to double check what the nurses and doctors are doing;

I research everything before I make a decision in medical affairs;

asking for medical records after every event;

I research and obsess over every recommendation that a doctor gives to me before going forward;

I have learned that I must complete research, ask questions, and take control of my own life;

more diligent in who cares for my son;

more careful to check on the surgeon and his knowledge and training of his staff;

I tend to double check any changes in medication or care;

I will never take a family member/child to the ER without a back up person to hear and witness;

I avoid going to see a Doctor;

I never want to leave my child's side when he is inpatient;

I am very cautious when approaching any medical situation and advise all of my friends and family

members to be also;

I will not leave any family member in the acute care setting AT ANY TIME [*sic*] without me or

another family member in attendance, even to ED, procedures etc;

Reports reflecting a nearly compulsive need to protect others from harm were common among family members. However, actions taken to protect others from harm require a commitment of time and resources as noted by one family member, "My kids have turned into teen-agers and I missed it. I became totally absorbed in correcting this failure in our healthcare system" (FM 87). Table 15 lists words and phrases used by family members to describe emotional distress that continued long after the medical error experience.

Family members with loved ones harmed by hospital acquired infections were especially concerned about protecting self or others from harm. For example a family member wrote, "I still feel that there is not enough being done to prevent these diseases from being contracted in a healthcare facility where one should feel safe" (FM 118). These concerns prompt action as reported by a family member, "I asked the ER physician's assistant if he had washed his hands. He made me repeat the question 3 times and he was VERY offended that I asked. I am offended that he was offended & filed a complaint with the hospital" (FM 119). Another family member noted, "Difficulty feeling completely positive about the future because 'it could happen again.' Any positive event has an underlying concern that it happening again would ruin the positive event" (FM 121). And, some report avoidance of medical care because of their safety concerns. For example, a family member stated, "I have personally postponed some routine diagnostic tests (colonoscopy, e.g.) to avoid exposure" (FM 122). Another family member wrote, "But I can't stand the thought of dying of something so horrible just because of unsantitary [*sic*] conditions. ITs [*sic*] a struggle to put it aside and get my medical test" (FM 107).

Some family members seemed to feel as if they betrayed a loved one when they did not satisfactorily protect the loved one from medical harm. For instance, this parent wrote, "We are good parents who were suppose [*sic*] to protect our daughter, not allow ourselves to be bamboozled by these doctors and hospital. Things like this don't happen to us, so we thought" (FM

Table 15

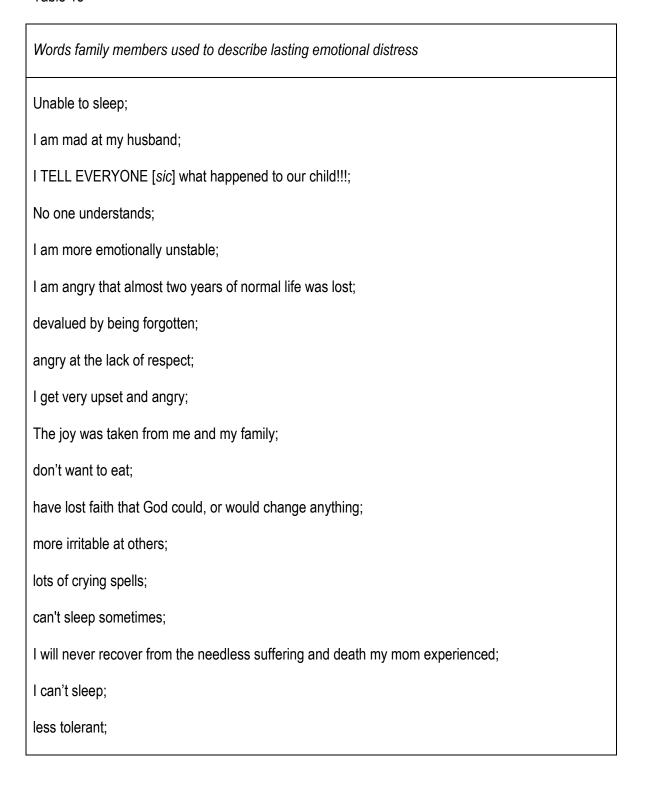| Words family members used to describe lasting emotional distress |
|---|
| Unable to sleep; |
| I am mad at my husband; |
| I TELL EVERYONE [*sic*] what happened to our child!!!; |
| No one understands; |
| I am more emotionally unstable; |
| I am angry that almost two years of normal life was lost; |
| devalued by being forgotten; |
| angry at the lack of respect; |
| I get very upset and angry; |
| The joy was taken from me and my family; |
| don't want to eat; |
| have lost faith that God could, or would change anything; |
| more irritable at others; |
| lots of crying spells; |
| can't sleep sometimes; |
| I will never recover from the needless suffering and death my mom experienced; |
| I can't sleep; |
| less tolerant; |

Table 15 c*ontinued*

Words family members used to describe lasting emotional distress
completely hopeless; there is a constant worry; make it my business to be vigilant in any healthcare for myself and family;   lose patience with other peoples' complaints I am experiencing many different emotions, including fear, guilt, anger; become upset easily; sought counseling to deal with feelings of guilt and panic around not getting the help we needed for   our mom;

11). Many family members indicated they had trusted healthcare professionals because of "a

sacred trust the public puts in them to do things right" (FM 33). And, trust in medicine was often

mentioned as contributing to the family member's response to the medical error experience. For

example, this family member stated:

> I live with the thoughts of how a system that I soo [*sic*] trusted could have failed her/us
> when we needed it. I think of if this happened to me/us with all of the experience how
> many other families have been damaged and DIDN'T [*sic*] know it because of lack of
> experience. (FM 65)

Another family member wrote, "I knew he was going to die, but to die at the hand of someone you

trusted makes me sick" (FM 60).

An explanation for not trusting healthcare professionals was given by one family member, "I

feel most providers are overextended and do not take adequate time to genuinely care for their

patients" (FM 45). Another family member explained the consequences of not trusting, "...no peace of mind, no faith, no trust in healthcare at all for me or family, horrible way to live" (FM 63). Table 16 lists words and phrases family members used when describing trust in medicine.

Healthcare professionals had a particularly difficult time following medical error injury to a loved one. One nurse wrote, "I have always been a skeptic of medical professional. I have seen far too many errors in my [many] years as a nurse. The medical error simply confirmed my suspicions" (FM 75). Another healthcare professional that reported the death of a child as a result of a medical error feels the entire system is to blame and stated, "I have become outraged at what passes for healthcare in this country" (FM 12). This sense that the system is at fault is echoed by another family member, "As an RN I am well aware of patient safety and system issues and do not blame the LPN in any way – she was just at the sharp end" (FM 18).

Some healthcare professionals reported feeling responsible for the medical error. For example, one nurse wrote, "I feel guilty and responsible for letting him have the surgery to begin with, and not staying with him to guard him from the doctors" (FM 25). Another nurse noted how hard it is to recover from failing to notice a colleague's error:

> My life will never be the same. I try to avoid thinking about it but is is still as clear as the day it happened in my memory. I feel traumatized by the mistake and guilty that I should have noticed the mistake. I feel it more acutely because I am a nurse myself and was my [loved one's] primary care giver. I believe this add[s] to the feelings of guilt. I realize that I should not feel guilty but I am regardless. I find it hard to complete this survey as it has made me think about something very hurtful. My [other family members] are also traumatized by the experience. (FM 125)

Another healthcare professional stated, "I work in the profession and was so upset by what I consider my colleagues failing my family" (FM 27). Summing up the consequences of the ordeal, the healthcare professional wrote, "I have had several medical issues over the last few years that have lead me to be very protective of who cares for me and how we collaborate" (FM 27).

Table 16

Words family members used when describing trust in medicine

no trust left;

they have no idea what do no harm really means;

not trusting of people in the medical field;

a greatly diminished level of trust with the field;

I don't trust doctors like I use to;

lost trust in my child's doctors, more protective;

My trust in doctors has decreased;

I do not trust them;

lack of trust in her providers;

afraid of the medical profession;

trust is no longer possible;

I am unable to trust medical providers;

I don't trust doctors and others in the medical profession;

I am untrusting of everyone;

do not have confidence that the right thing will happen to loved ones in a hospital;

extremely distrustful of the medical profession;

do not trust Medical personnel like I used to;

Table 16 c*ontinues*

Table 16 c*ontinued*

Words family members used when describing trust in medicine
I do not trust doctors since this experience; asked not to have this physician; I have less confidence in medical professionals generally speaking; not as confident in our medical clinic as I was before the incident; I never totally take a medical person at their word; never, ever trust a doctor

The way the medical error was handled had a profound effect on healthcare professionals with injured loved ones. For example, one distressed healthcare professional wrote about a preventable medical error that caused painful suffering and death in a loved one:

> It has taken years to forgive myself, for not going right away to oversee the care of my [loved one]. It took years before I could tell anyone about it without crying. I felt numb for so long. I miss my [loved one] every day and can't imagine the pain he went through before he died. (FM 62)

Another healthcare professional was distressed over the response of colleagues:

> I work with physicians every day. It was disturbing to see them protect a "bad egg" even when they knew he was at fault. It convinced me that more needs to be done to monitor physician performance - with outside intervention. (FM 49)

In addition to the emotional distress and lack of trust noted by healthcare professionals and family members, detailed accounts of how family felt their lives changed included reports of decreased capacity to function on a daily basis and more problems in life since the medical error occurred. One family member described the ordeal:

I returned from where I had been living to my parent's house to take care of my disabled [loved one]. In the process giving up my career, friends, etc. to help in the aftermath of my [loved one's] unexpected death. The excessive stress of that situation combined with my attempt to have accountability for the preventable medical tragedy took a major toll on my health. Its ten years later and I'm still trying to recapture my potential. (FM 83)

The entire family may be harmed by the experience; one family member explained, "It has affected our marriage even [though] we are still married. We love each other but it is different because we are both lost in our own worlds…" (FM 6). The family member continued, "The worse part is watching our son. He is afraid of hospitals and is afraid if someone goes into the hospital they will die and never come back home" (FM6). This family member summed up the daily torment in a sentence, "I've often said I wish people could experience our life for just a week and they would see the world we live in daily" (FM 6). The negative changes are multifaceted, as one family member wrote, "The costs of taking our [loved one] out of state for medical treatment have placed a huge financial burden on our family. The emotional stress on our family has been even worse" (FM 9).

In addition to stress at home, family members reported trouble at work, in social situations, and in being able to do the things that they needed to do. Table 17 lists words and phrases used by family members to describe how difficult daily functioning can be after a medical error experience.

The way the medical error was handled seemed to add to the distress of some family members. One family member explained, "This error has impacted our family financially and emotionally. For 5 1/2 years our [loved one] was treated by specialists at the hospital where this error occurred--the staff at this [hospital] knew our [loved one] and our family well" (FM 9). However, the medical error was not addressed by the healthcare providers. The family member wrote, "After the error, the hospital told us that we should take our [loved one] elsewhere for treatment--and this has meant starting over again with a new center and/or physicians" (FM 9).

Table 17

Words and phrases family members use to describe daily struggles
financially strapped;
love life is non-existent;
avoids social situations;
anxiety attacks last year;
it caused my parents to switch practioners;
relationship among my siblings is gone;
had to move her to assisted living;
you don't talk about it;
all aspects of all our lives have been changed;
I am much more serious minded about everything;
avoid some family functions;
can't take care of her home and yard;
life isn't much different besides being a bit angry at times;
lost his job; doesn't keep in touch with friends;
live in poverty;
had to cut back on work and hire home care;
more pessimistic;
my family is shattered;

Table 17 co*ntinued*

Words and phrases family members use to describe daily struggles
have not gone shopping since the incident; the issues I have outlined are only scratching the surface; difficulty feeling completely positive about the future; I nearly went bankrupt; relationships with family and friends have changed; developed anxiety disorder; having to change our whole way of life; isolating; So, you don't talk about it. But, you're always thinking about it; How to sum up nearly 10 years of near hell at times...

Many family members felt the need to seek justice for the harm, as explained by this family

member:

> I have nightmares every night. It's always the same. The doctors voice berating me while
> the picture of me holding my mom during the seizure and cardiac arrest plays over and
> over and over. Most nights I wake myself up. it takes awhile to get back to sleep. to calm
> down. I feel alot of guilt for my mother's death. I feel like, if I had not been asking questions
> about medicines or procedures and keeping up on things, if [maybe] they would have
> treated her better and helped her more. while I know my family tells me that it was not my
> fault, they needed a scapegoat. I am accepting that responsibility until justice is done for
> her. (FM 110)

Family members reporting a desire for justice, feelings of distress, or a lack of trust commonly

report that few disclosure strategies were put into practice following the medical error experience.

One parent described how a child suffered a stroke and brain damage after a healthcare professional negligently connected the child's feeding tube to an IV line. The medical error caused considerable harm and distress; however, the healthcare professional's response caused even greater harm. The parent wrote, "Nurse [went] back to work immediately and tried to talk to me as if nothing ever happened" (FM 10). Similarly, shocking harm occurring to another family member's loved one was ignored as reported by a spouse, "The worst was that my husband was not the same person ever again and his caregivers would not acknowledge that" (FM 117). Table 18 lists other responses of healthcare professionals as reported by family members.

As a result of the response of healthcare professionals, family members described being worried "about this happening again to other children since it has never been officially acknowledged" (FM 110) or being "still haunted by the deception" (FM 71). One family member noted being constantly bothered about not being given a full account and described the feeling as something that "still gnaws at my soul" (FM 11). These feelings seem to drive some family members to take action. Table 19 lists words and phrases family members used to describe actions taken in response to healthcare professionals not providing adequate disclosure following the medical error experience.

One family member believed that there were many individuals psychologically affected by a medical error incident. The family member stated, "Obviously My [loved one] was so harmed and died as a result. My family were [*sic*] devastated beyond imagination but have grown stronger as a result... the third [victims] were the providers. These were good people who really screwed up"

The failure to obtain adequate information or explanation was often mentioned as a reason family took legal action. Many family members' reasons for taking legal action were similar to the following family member's reason for taking legal action:

Table 18

| Words family members used to describe the healthcare professionals' response to the medical error experience. |

the hospital has not disclosed;

nothing from the hospital or the nurse;

I was never told the full extent of her injuries;

no one has ever apologized;

doctors have never had to acknowledge that wrong doing or be held accountable;

stone-wall us in our attempts gain more information;

the doctor would not give me a cause of death;

never was a single word of apology said;

no one ever contacted me;

the hospital won't explain their role in this at all;

health care professionals covered up for the one responsible;

doctor never openly acknowledged or apologized for his error;

changing the dates the medication was given in the records;

nothing was done to the physician;

 would not meet with us;

no apologies were ever pursued or received;

we were never given an explanation;

Table 18 c*ontinued*

Words family members used to describe the healthcare professionals' response to the medical error experience.
records also showed that the doctors had lied about facts I know that they lie to cover up mistakes; the hospital could release that information, but they refused; they also told us they would investigate but that we could not be told anything about the investigation or its outcome;

> The ONLY reason we sued was so it would go on his record and other consumers would have a red flag…. Otherwise, nobody would ever know. It would never be counted - if it happened again - nobody would say it had happened before. (FM 78)

No family members recommended litigation. One family member stated that the lawsuit, "took 7 years to be finalized and I would not recommend that process to anyone. Every new deposition opened the scars again" (FM 72). Still, the need to protect others from similar harm was often repeated in context with the decision to take legal action:

> I feel bitter about what happened to my father and angry that the hospital wasn't fined or punished for it. I think the state inspectors of this type of argument all know the hospital administrators so the latter get a slap on the wrist and then go back to their usual methods. I've tried very hard to avenge my father's death by getting the hospital to take responsibility for it and change its practices so no other family has to go through what mine has.(FM111)

Table 20 lists words and phrases family members used when providing information about litigation.

Although family members reported the medical error experience to be extraordinarily traumatizing, some family members reported meaningful personal growth as a result of the

Table 19

Words family members used to describe actions taken following inadequate disclosure
I contacted the hospital after 20 months of no sleep;
it has taken all of my resources to find out the truth;
I have been to my state and local government for help;
the autopsy supported what I witnessed;
I wrote a follow up letter to the hospital and the doctor, and never received any response;
I received very unsatisfactory feedback from them;
we sued;
I had to investigate what happened in that hospital on my own;
they could not tell me why he died;

experience. Frequently mentioned growth experiences included strengthening of family relationships, renewing faith practices, affiliating with a patient advocacy organization, working to bring awareness of the problem of medical harm, and promoting legislation to stop preventable medical error. Table 21 lists words and phrases family members used to describe coping methods or sources of support in the aftermath of the ordeal.

Table 20

Words family members used to explain or describe litigation
Through filing a medical malpractice lawsuit, I saw the darkness in people: pure evil;

I'm consulting a lawyer;

I need to know they are restricted from giving this drug;

We even filed a complaint with the State Attorney General's Office;

I wish my family would have sued him. They need to be taught a lesson;

a very corrupt system;

I pursued this case with administrators of the hospital;

I do not fit the law to get justice;

I do not want this to happen to anyone else;

I did not have the emotional stamina to wage that fight at the time;

 could not get legal respentation [*sic*];

it is wrong that we are now not able to speak about it because we did take the action;

we've since heard that he has had similar issue since then - and nothing has been done;

I had no time or energy to pursue a claim;

I have become part of the community of sufferers for whom justice was denied;

there is no responsible method of action to address the medical fraud |

Table 21

Words family members used to describe coping in the aftermath of the ordeal
it helps having people who have gone through similar experience share their stories;
all and all we are a Strong Family in the Faith and We Trust God that HE Will See Us Through;
I have fought to make changes in a positive way;
PULSE has been a light in a dark tunnel;
I have become an activist for patients' rights;
one should cherish every moment;
trying to work on legislation to help save others;
realize how fragile life is - try to appreciate good things in life more;
trying to be at peace;
I have become an advocate for people in the medical system;
have grown stronger as a result;
I volunteer many hours on committees for patient safety;
we have a positive outlook, lots of faith and great support;
I have been lucky to have a loving and supportive family;
I have dedicated my life to stopping the horror of hospital infections;
trying to accomplish a few projects on my list everyday;
I wrote a book;
The most important job I do now is working for patient safety;
I have worked for 5 years to bring about patient safety reform

Chapter IV

Discussion

This study investigated the experiences of people with a loved one who was injured or died as a result of medical error, with a particular eye towards understanding the traumatic nature of the experience as well as the possibility that the experience would lead to posttraumatic symptoms such as PTSD. The study incorporated quantitative and qualitative methods and the results were remarkably consistent across these two methods. This study found that, although these family members did not directly experience the medical error, they responded to the medical error injury of a relative as if they had experienced the trauma directly. Quantitative findings from this study showed that 37.5 % of the family members in this population suffered from long-lasting symptoms of trauma as measured by a standard PTSD instrument. Family members are therefore likely to be at increased risk of developing PTSD as described in the *DSM-IV-TR* (2000).

Qualitative findings supported the quantitative findings. These family members indicated that they experienced an intensely emotional reaction to the event and that they suffered from intrusive memories, emotional numbing, increased anxiety, heightened arousal, and avoidance of situations reminiscent of the experience. These findings are similar to those of other studies in which individuals reported initially reacting to a traumatic event with feelings of intense emotion and developing more enduring symptoms characteristic of PTSD (Briere & Scott, 2006; Herman, 1997).The findings indicate that the experience of having a family member severely or fatally

harmed by a medical error is a traumatic event, similar (at least in some respects) to other traumatic events such as combat, rape, or natural disasters (Breslau et al., 1998).

In addition to the findings related to trauma symptoms, this study found that effective disclosure of the medical error mitigated the family's response. In this population, family members were less emotional and had fewer traumatic symptoms when healthcare professionals put into practice common disclosure strategies, sincerely communicating essential information. The quantitative data and the family members' personal statements both support this finding and indicate that the failure of a healthcare professional to adequately disclose information related to the medical error experience increases family distress. This finding supports claims that an adequate disclosure by a healthcare professional would make the medical error experience less disturbing to the family (see Elder, Jacobson, Zink, & Hasse, 2005; Gallagher et al., 2003; Vincent, Pincus, & Scurr, 1993).

<center>Trauma Symptoms</center>

For family, the symptoms of trauma that follow the medical error event are profound. In this study, almost 40% of the family members reported experiencing some symptoms of PTSD. Moreover, nearly a third of respondents experienced clinically significant symptomatology and 1 in 5 experienced severe symptoms of trauma. In other words, many people experienced symptoms and, when experienced, these symptoms were usually strong.

This finding is important, in part because it was unexpected. Based on the work of Breslau and associates (1998) it was predicted that only 9% of participants (at most) would report experiencing symptoms of trauma. This was seen as a conservatively large estimate, because it was based on the overall rate of PTSD for all types of trauma experiences in Breslau's study, including violent traumas such as assault and serious accident, non-violent trauma, such as

discovering a dead body, and secondary trauma such as witnessing the injury of another. Four times as many participants reported trauma symptoms as was predicted. What is more, the rate of PTSD reported in this group of family members is substantially higher than the rate for assaultive violence (21%) reported by Breslau and associates. Thus, based on the findings in this study it is reasonable to assert that experiencing the medical error injury of a loved one is, at least for some family members, a highy traumatic event, on a par with events that (on the surface) seem much worse – such as rape or assault.

The findings in this study are important for another reason: the quantitative findings are confirmed by the qualitative findings. Overall PTSD is better understood in light of the essential components and an examination of each decisive factor exposes the impact of the ordeal for family members. In both the quantitative and qualitative data, these family members reported experiencing emotional distress at the time of the medical error event or soon after, and reported experiencing symptoms from the three clusters of symptoms associated with PTSD (*DSM-IV-TR;* Criterion A2, B, C, and D).

The emotional reaction to the medical error was intense. As indicated by the *Peritraumatic Distress* scores, nearly two-thirds of the family members reported feelings of distress during the medical error experience or when learning about the medical error. Personal statements described family members' emotional reactions to the event and included descriptions of feeling significant fear, helplessness, and horror as well as guilt, shame and distress, all of which are implicated in PTSD. These qualitative findings therefore support the *Peritraumatic Distress* score. Together the *Peritraumatic Distress* scores and the family members' descriptions revealed the intensity of the initial reaction to the medical error experience. For some family members, it was as if time stopped at the moment of the medical error experience. For example, one family member stated, "Everything changed. [Date removed] became the first day of the rest of our lives" (FM 87). Family

members also reported being distressed beyond the time of the medical error event, in some cases as long as ten years after.

Results for the *Reexperiencing* scale showed that nearly 4 out of 5 family members reported experiencing recurring and distressful traumatic memories of the event. Similar to the *Peritraumatic Distress* scale results, the quantitative data yielded findings that were confirmed by comparison to the findings in the qualitative data. Specifically, these family members reported experiencing certain long-lasting PTSD symptoms including nightmares, flashbacks, and upsetting thoughts or memories of the experience; thoughts of the medical error experience that were difficult to get out of their head; and distress when reminded of the medical error experience.

In addition to these traumatic memories, family members reported experiencing common symptoms of avoidance. The *Avoidance* scale reflects family members' attempts to avoid people and situations that might cause distressing memories or attempts to constrict general feelings associated with awareness. Results from this measure indicated that one-third of the family members report experiencing avoidance symptoms. Thus, the symptom appeared less frequently than other symptoms such as reexperiencing. However, family members' personal statements describing how life had changed since the medical error experience suggested that other factors should be considered when interpreting these results. The relatively infrequent occurrence of this symptom cluster is not surprising given the method of recruitment of study participants and the nature of illness which requires ongoing need for medical care. These possible explanations for the low frequency of reported avoidance symptoms are considered below.

First, the method of recruitment of participants through patient safety organizations and the high number of family members indicating involvement in patient advocacy initiatives is relevant (see Table 1, Source of the Respondent). Almost by definition, individuals promoting patient safety are not avoiding situations that might cause traumatic medical memories. Active participation in

patient safety organizations may help family members cope with the stress of the ordeal and may provide support that is otherwise not available. In addition, connecting to other individuals with similar experiences through patient safety organizations may be a coping strategy that mitigates the traumatic effect of the medical error experience. For example, one family member noted being "involved with a patient safety organization that has truly been a source of healing" (FM 11). Previous studies of other populations dealing with trauma have found that avoidance of problems or situations reminiscent of a traumatic event is the least effective way to handle exposure to trauma (Herman 1997). Also, other studies found that stress is reduced when individuals find out more about a situation and take action based on that information (Brown et al., 2002; Dewe & Guest, 1990). Indeed, many family members reported making efforts to obtain information about the medical error, taking legal action to stop unsafe practices, sharing personal stories of their experience to warn others of similar harm, or working to expose the injustice of the system.

Next, the nature of illness and the need to seek medical care when one is ill must be considered when evaluating the *Avoidance* score for this group. Individuals suffering from chronic illness or permanent injury may not be able to avoid seeking medical care; therefore, some family members may be forced to confront stressful medical situations. And, while some family members did note persistent avoidance of medical care, family members also noted experiencing great distress when they or someone they knew was in need of medical care. In addition, many family members reported making efforts to research a medical condition prior to seeking medical care and reported carrying an advocate with them when seeking personal medical care – indicating a lack of trust in the medical system (i.e., trying to avoid relying on the expertise and good intentions of medical personnel and, instead, relying on oneself as much as possible).

These findings indicate that complete avoidance of medical care is difficult. Taken together, a propensity for advocacy, the opportunity to seek support through a patient safety organization,

combined with the inability to avoid confronting stressful medical situations may result in lower

Avoidance scores. Furthermore, some family members described feelings of general emotional

numbness that usually indicate symptoms of avoidance. For example, family members wrote "I'll

never feel true happiness" (FM 124), "Life began to end the day the hospital killed my mother" (FM

70), and "I wish I could disappear" (FM 6). Moreover, family members commonly reported taking

steps to protect others from similar medical harm (e.g., FM 23, FM 78, FM 111) and restricting their

lives seemingly in an attempt to control a persistent fear of needing medical care (e.g., FM 85, FM

87). In other words, they were trying to avoid being in a similar situation in the future.

 Thus, the aforementioned descriptions of the remarkable measures these family members

take to deal with the stress of the medical error event may reflect avoidance efforts subtle and

sophisticated enough to be best assessed in structured clinical interviews or in a psychological test

designed specifically to measure responses to a medical error. For this reason, the DAPS

assessment may not reflect the actual avoidance response of some family members and the

marginal *Avoidance* score reported in this study may cause some family members to be wrongly

placed in the non-PTSD group. It is also important to remember that individuals often report

experiencing debilitating symptoms of trauma and suffering from significant distress without

reaching full diagnostic levels of PTSD (e.g., Tedstone & Tarrier, 2003). Therefore, although some

individuals in this study may not meet the avoidance criteria for PTSD, they may still be suffering

from serious symptoms of trauma – especially when dealing with illness or seeking medical care as

previously explained.

 The continual need for family members to seek medical care may explain, in part, the

heightened hyperarousal response in family members. Results from the *Hyperarousal* scale

suggest a high level of arousal in nearly two-thirds of the family members. In both the

questionnaire and in the descriptions of how life had changed since the medical error event, family

members reported experiencing tension, sleeping difficulties, irritability, and hypervigilance in medical situations. These findings support findings in other studies where anger and frustration were reported by patients seeking medical care (Elder, Jacobson, Zink, & Hasse, 2005; Gallagher et al., 2003). In addition, in the personal statements, family members specifically reported experiencing fear related to the medical error experience including the fear of needing medical care and the fear of being harmed when receiving future medical care. The fear of medical injury goes beyond self to include other family members and close associates that may need medical care. Certain answers to the open response items suggest that family members fear of future injury is exacerbated when information is withheld or when steps are not taken to prevent similar harm from occurring to others. For example, one family member wrote,

> The medical experience has left us looking at everyone in a wheelchair wondering if was because of the same surgeons. Also feeling helpless to help the people who have gone under the same knife since [date removed] in the same O.R. who came out the same way. No way to stop it from happening to you or anyone else. (FM 23)

For this reason, some family members may respond to the medical error experience by being hypervigilant to the potential for harm in a medical setting. These family members may take measures to avoid medical care or may extensively prepare for medical situations – either response will likely contribute to symptoms of trauma. Thus, our data are similar to and support patient response reports evaluated by other researchers (Elder, Jacobson, Zink, & Hasse, 2005; Vincent, Pincus, & Scurr, 1993).)

Altogether, this group's *Peritraumatic Distress*, *Reexperiencing*, *Avoidance*, and *Hyperarousal* scale findings and the qualitative data provide evidence that these family members experience symptoms of trauma following the medical error injury of a loved one. Although a clinical evaluation of each individual is necessary before the presence or absence of PTSD can be rigorously established, the results from this study indicate that many family members in this population are

suffering from enormous emotional pain and are at increased risk of full-blown PTSD. Still, the medical error experience and the full breadth of trauma resulting from the medical error experience is not easily categorized by a psychological test and is not fully explained by a listing of symptoms. For this reason, it is important to carefully consider how the traumatic experience changed the lives of the family members in this study.

The Aftermath: Impairment

Traumatic events provoke powerful emotions that can challenge normal daily functioning. In this study, the *Posttraumatic Impairment* scale reflects psychosocial impairment as put forth in the *DSM-IV-TR* (2000) and the overall result suggests that family members do not suffer from general debilitating impairment. However, a review of the responses to the individual scale items and descriptions from family member personal statements suggest otherwise. First, respondents reported weekly problems in three domains as indicated by a score of ≥ 2 on selected *Posttraumatic Impairment* scale items. Specifically, trouble was found in problems in relationships (item 45; M = 2.10) or in difficulties at work, school, or in social situations (item 53; M = 2.03) or in the inability to do things family member needed to do (item 61; M = 2.15). Using the DAPS interpretive rules, individuals reporting scores such as these likely experience symptoms of impairment that can be unbearable (Briere, 2001; *DSM-TR-IV*; Criterion F).

 Additionally, the qualitative information provides evidence of family members being overwhelmed in the aftermath of the medical error experience. Generally, family members in this group reported experiencing high anxiety, intrusive memories, and emotional numbness and making efforts to prevent similar harm from occurring to others. More specifically, family members indicated persistent struggles: tormented by distressing thoughts of the medical error event, suffering from feelings of guilt and shame for failing to protect a loved one from harm, bounded by

feelings of helplessness against a complicated and formidable medical system, and fearfully aware of the ever-present potential need for future medical care. Daily efforts to handle this kind of psychosocial harm likely narrow and diminish the quality of life for family members. Of importance when considering the realities of a family member's reduced ability to enjoy daily life is the other finding from this study: better communication seems to mitigate the symptoms of trauma.

Communication

Good communication is fundamental to medicine. Generally, it was expected that better communication ratings – especially those scores related to disclosure – would be associated with reduced symptoms of trauma reported by family members. The study findings indicate that better quality of the disclosure is associated with reduced trauma symptoms in family members; however, data related to communication indicate that healthcare professionals consistently failed at communicating important information to family.

Healthcare professionals primarily communicate directly with the patient. Still, family members may be provided information if they are with the patient or if they are designated by the patient to receive information. Family members in this study noted being intimately involved in the medical care of their loved ones. For example, nearly half (43%, $n = 55$) of the family members reported being the primary caregiver for their loved one and over one-third (37%, $n = 47$) of the family members reported being with the loved one when they learned about the medical error. Only nine of the family members reported not being certain about the details of the medical care. Altogether, family members completed three measures related to communication; a summary of these measures follow.

The group's *Physicians Communication* scale (Heisler et al., 2007) results suggested that communication prior to the medical error experience was not sufficient. Additional evidence is

found in the item by item analysis of the scale where the highest rated item was "Told you what to expect from the treatment" (*M* 2.32, range 1 = *Poor* to 5 = *Excellent*). Patient care may benefit when family members are provided with treatment information, so there is some concern when even the best rated item was no better than fair. Moreover, the provision of information is essential when family members are responsible for the loved one's care away from the medical facility. In addition, in the qualitative results, many family members' descriptions of the medical error experience included some evidence of the failure to have important information communicated prior to or during the delivery of medical care. Some examples of the failure to communicate important information included off label use of drugs during the delivery of critical care and improper placement of invasive tubes. Also, the *Physicians Communication* scale was negatively correlated to six of seven specific trauma scales with the most significant association being the *Hyperarousal* subscale. Inadequate information prior to medical procedures or treatment may contribute to feelings of helplessness or a fear of the unknown. These feelings may cause a family member to plan on being on the alert in future medical situations.

The second measure that informed the communication findings was the *Disclosure Strategies* scale (COPIC, 2004, 2007). In this group, two-thirds of the family members reported having no disclosure strategies put into practice by healthcare providers. In addition, three-quarters of the family members reported not being given an apology and the vast majority (more than 80%) indicated that they were not provided key facts about the medical error incident.

There was partial support for asserting that symptoms of trauma are lessened when healthcare providers use common disclosure strategies. The number of disclosure strategies was negatively correlated to the *Posttraumatic Stress - Total* scale and the *Posttraumatic Impairment* scale indicating that as healthcare professionals use more strategies the overall symptoms of trauma and the resulting impairment decrease. The analysis of the qualitative data yielded results

that confirmed the quantitative findings for the reported number of disclosure strategies used by healthcare professionals. These results are not surprising in view of previous studies of medical error and disclosure that found that disclosure often does not occur (Allman, 1998; Blendon, et. al., 2002; Gallagher, Studdert & Levinson, 2007) and that medical errors are commonly underreported (Blendon et al., 2002; Cullen, Bates, Cooper, Nemeskal, Small, & Leape, 1995; Hobgood, Xie, Weiner, & Hooker, 2004; Taylor et al., 2004). Still, the low number of disclosure strategies put into practice by healthcare professionals as reported by the family members in this study is disturbing especially when so many (nearly three-quarters) of the family members report the injury to their loved one as being "Extremely serious" (e.g., died or might have died).

The final measure for healthcare professional's communication of information to the family members was the *Quality of Disclosure* scale (COPIC, 2004, 2007). Overall, nearly three-quarters of family members rated the quality of the healthcare professionals' disclosure of the medical error as only slightly better than *Poor.* In addition, the data revealed that very few (less than 15%) of family members reported being told about the medical error by a healthcare professional and that even fewer (less than 8%) of family members reported being provided with a good quality disclosure. *Quality of Disclosure* was negatively correlated with the measures for symptoms of trauma (i.e., *Hyperarousal, Posttraumatic Impairment,* and *Reexperiencing).* Thus, the lack of good quality disclosures is likely one of the reasons for the high rates of PTSD symptoms seen in this sample. The analysis of the qualitative data yields results that support this finding. Most family members reported receiving little or no explanation and some reported that information was purposefully withheld or was provided only after legal steps were taken. The provision of an honest and compassionate explanation, the promise of an investigation, and adequate compensation for the medical error experience would clearly make the medical error experience less disturbing to

these family members. Therefore, the failure of healthcare professionals to communicate important medical information to family members is difficult to understand.

There are many possible reasons family members might expect to receive information about medical care when they are involved in the care of a loved one – including information regarding possible medical error. First, the American Medical Association (AMA) and others take the ethical position that health care personnel have a duty to report his or her errors and the errors of others (Joint Commission on Accreditation of Healthcare Organizations, 2001; American Medical Association, 1981; American Nurses Association, 2002). Next, healthcare providers realize that their acknowledgment and apology for a medical error can be immensely healing (Banja, 2003; Massachusetts Coalition for the Prevention of Medical Errors, 2006). And, previous studies have found that the failure of the healthcare provider to disclose a medical error, acknowledge responsibility, apologize, and work to ensure that the error does not recur has negative consequences including impaired patient trust, reduced patient satisfaction, and increased possibility of a medical malpractice lawsuit (Gallagher, et al., 2003; Mazor, et al., 2004; Vincent, 2002). Furthermore, when healthcare professionals do not communicate well with family members, the family members may suspect that an error has occurred. Thoughts that an error occurred may increase if information related to the health of the patient is not provided or, if provided, is unclear or incomplete. These factors likely contribute to the expectation that information will be provided, especially after an unintended event in the delivery of medical care occurs.

A failure to communicate information, to explain unfortunate circumstances, or to account for less than optimal outcomes has been found to increase the known emotional response to injury in medicine (Hickson, Clayton, Githens & Sloan, 1992; Mazor et al., 2004; Vincent, Pincus, & Scurr, 1993). Information provided by the healthcare professionals that participated in this study underscores these concerns. Several healthcare professionals reported having a loved one injured

by medical error and indicated not only suffering symptoms of trauma related to the experience but also being distressed by the response of colleagues. This finding supports findings from studies dealing with the significant emotional distress of healthcare professionals following medical errors (Christensen, Levinson, & Dunn, 1992; Waterman et al., 2007; Wu 2000). Thus, given the overwhelming evidence that good communication is ethical, helpful, and prevents or mitigates a number of negative consequences associated with medical care, a healthcare professional's failure to effectively communicate with the family following a medical error experience is difficult to justify.

Relevant to the issue of communication and to this study, Mello and Brennan (2002) assert that medical care professional's concerns about litigation result in nondisclosure of medical errors. In this study, more than two-thirds of the family members reported <u>not</u> taking legal action following the medical error experience. Analysis of the data yielded no significant correlation for legal action taken and any of the communication measures (*Physicians Communication, Disclosure Strategies, or Quality of Disclosure*). These findings suggest that medical care professionals' beliefs about the relationship between open communication with patients and litigation are inaccurate. If there is not an increased risk of litigation, there is little reason to provide anything less than adequate communication. Furthermore, such communication may serve as a necessary support resource for family members and as a shield against family members' feelings of helplessness. Clearly, a more thorough investigation of this issue is needed.

The Burden of Medical Error

In addition to symptoms of trauma, the risk of PTSD, and a reduced ability to function well on a daily basis, for some family members the medical error may result in impaired trust in the medical profession and a decision to pursue medical malpractice litigation.

Trust may be an essential part of medicine. To seek medical care, patients must be confident that physicians are skilled and capable, must believe that physicians are willing to be accountable for their actions or inactions, and must rely on physicians to "give their patients' welfare the highest priority" (Mechanic & Schlesinger 1996, p. 1693). In this study, family members trust in medical professionals (as measured by the Wake Forest Medical Profession Trust scale) was low overall and substantially lower than the average score reported in previous research on a large national sample (Dugan, Trachtenberg, & Hall, 2005). In fact, only 1 in 10 of the family members in this study reported levels of trust similar to the average participant in Dugan, Trachtenberg, and Hall's national sample. These findings are confirmed in the answers family members provided when asked to describe how life had changed following the medical error experience.

Good communication between healthcare professionals and patients and family members likely creates trust and encourages general confidence in medicine. The finding of reduced trust in this study may be explained, in part, by the low incidence of full disclosure reported by family members (in addition, of course, to the loss of trust due to the medical error experience itself). Trust may be betrayed when those responsible for an individual's medical care do not explain the medical error to the patient or the patient's family members and when the responsible party does not acknowledge harm, apologize for harm, or take steps to prevent a reoccurrence of the error causing harm. Such a betrayal of trust may have far-reaching consequences; in fact, betrayal of trust by one physician has reportedly reduced an individual's trust of other physicians, the health care facility in which the physician is employed, and the profession of medicine in general (Goold, 2001; Mechanic, 1998).

Trust violations may result in emotional responses. Vincent (2001) asserted that medical error injury causes emotionally powerful responses because patients placed considerable trust in those who harmed them and because patients necessarily must trust medical professionals to provide

future health care. And, Hall (2005) connected trust-related emotional responses with the decision to take legal action following medical error. Asserting that the pursuit of litigation following medical error is the "primary method an injured patient can seek to assuage the strong sense of betrayal of trust" in "irreparably damaged" physician-patient relationships (p. 306), Hall claimed that some injured patients take legal action to "teach the doctor a lesson" or to "make the hospital pay" (p. 303). In this study, family members noted similar reasons for taking legal action. Moreover, taking legal action was positively correlated to *Peritraumatic Distress* – a measure of the reaction at the time of the event that is also strongly related to the family members' report of a more serious injury. Also important to this finding, May and Stengel (1990) report that those who sue their doctors tend to have more serious injuries, to possess a smaller number of status and power resources, and to need compensation for loss.

The findings from this study indicate that medical error experiences that result in more severe patient injury may yield greater rates of PTSD and its symptoms. The seriousness of the medical injury was positively correlated with the family members' reaction at the time of the medical error experience or upon learning about the medical error injury as well as with more long-lasting symptoms of trauma. Other research linking the seriousness of an injury with any psychological impact on the family members of the injured is not known. However, a previous study of heart transplant recipients and their primary caregivers found that recipients and caregivers both reported symptoms of PTSD (10.5%, 7.7% respectively) and Breslau and associates (1998) reported a 14% rate of PTSD when individuals learned about the unexpected death of a loved one. These rates are much lower than the rates found in the present study's family members. Clearly, more studies are necessary to tease apart the contribution of medical error to the development of PTSD in medical events that result in tragic disability or the loss of life. Moreover, based on the qualitative data in this study, future studies should consider how the serious injury or the death of a

loved one may require a family member's special attention and may affect the family member's relational, social, emotional, economic, or occupational resources (Hobfoll, 2001; Hobfoll, Dunahoo, & Monnier, 1995; Smith & Freedy, 2000).

The current study found greater risk of symptoms of trauma for the poor and the less educated following medical error experiences and found that lower levels of psychological distress in some family members may be the result of more education and higher education. Specifically, less educated family members report experiencing more distress at the time of the event and greater life difficulties; less affluent family members reported having more difficulties and trouble with life following the medical error experience. In another study, Cordova, Andrykowski, Kenady, McGrath, Sloan, and Redd (1995) found similar associations and reported a negative correlation between income and PTSD symptoms and between education and PTSD symptoms. These researchers reported that women diagnosed with life-threatening illness with higher income and more education experienced fewer symptoms of trauma. The sample of family members in this study consisted of mostly well-educated, middle income, Caucasian women. The low participation rate of ethnic minorities and individuals with less income suggest that this group is underrepresented. Thus, this investigation is limited in that those individuals with fewer resources and with a more diverse ethnicity might exhibit higher rates of PTSD and higher levels of distress. Still, although Kessler et al., (1995 National Cormorbidity Study) found no overall association of PTSD with social class in the general population, recent studies indicate important disparities in the quality of medical care and the access to medical care in minority populations (U.S. Department of Health and Human Services, 2008). Income and education may serve as buffers to trauma following medical error experiences because more educated and affluent individuals likely have access to better care outside of the medical setting as well as more resources for providing financial, psychological, and social support.

The range of medical care experiences that is possible within a vast system of sometimes complex medical care delivery prevents making specific claims regarding the psychological impact of medical error in family members of the injured. Nonetheless, the impact of medical error in the family members of the injured includes the real possibility of experiencing marked psychological distress at the time of the incident, of suffering repeated traumatic memories after the incident, of enduring increased fear when in need of medical care, of remaining watchfully vigilance when seeking medical care, of trying to control excessive arousal when reminded of the incident, and of confronting a greater probable risk of developing PTSD. Adding to this impact is the additional burden borne by family members when trust is lost, critical resources are lost, and loved ones suffer or die.

Limitations and Future Research

A number of limitations to this study should be considered. First, since the response rate is not known and a low response rate is assumed, the low response rate could create an unrepresentative sample that might enhance the effects of self-selection and limit the generalizability of these findings. Next, family members that are more upset by the injury may have been more likely to participate in this study and, if so, may partially explain the high rates of PTSD that were found.

In addition, this sample was not ethnically, economically, or educationally diverse, and, as mentioned in the discussion, the less educated and less affluent reported the highest symptoms of trauma. Consequently, similar investigations of more diverse populations likely would report higher rates of PTSD. For this reason, future researchers should modify the recruitment method used in this study to promote a more diverse selection of participants. Even so, in this study, several correlations were statistically significant and were supported in the qualitative data.

The personal statements collected in the open response items of the questionnaire provided beneficial data. However, the narratives were not without limitations. Some family members failed to provide enough detail for adequate interpretation of the nature of the medical error experience. Therefore, although the majority of the medical error experience descriptions contained substantial information, several medical error descriptions with sparse text were not able to be coded. Given the known scale of medical error events confirmed by medical and legal experts (see, Weiler, 1991), a medical error claim made by a family member should be believed and seriously considered. Still, some family members may interpret expected complications of illness, the progression of disease, or dire outcomes as medical error events – especially when information is not adequately communicated by healthcare professionals. Therefore, a more extensive replication of this study also could include a review of the patient's medical record to confirm the nature of the reported medical error experience, the clinical evaluation of the family member to confirm the response to the medical error experience; and the recruitment of a comparison group of family members that did not experience a medical error in the delivery of similar medical care to a loved one.

Another potential limitation to this study is the modification of the various measures for online administration. For this reason, a systematic examination of the questionnaire that includes comparison of the results from a paper and pencil version of the questionnaire to the results from the online version of the questionnaire is necessary and would facilitate greater generalizability of the findings. In addition, the availability of paper and pencil versions of the questionnaire might allow individuals without computer access to participate. Similarly, while a preliminary survey was conducted to check the content of the questionnaire, a more thorough evaluation of the scope and sequence of the measures included in the questionnaire would be prudent. For this reason, multiple versions of the questionnaire with random ordering of the measures should be

administered and the results compared to determine a more valid and reliable version of the questionnaire.

Future research should take note of the possibility that the measures used in this investigation may not be well-suited to the population of family members of the injured or to the issue of medical error. Family may present with varying degrees of vulnerability and different types of medical errors may cause varying degrees of stress. Therefore, consideration should be given to the development of an instrument tailored for this specific population. Moreover, greater understanding of the experience of family members would be possible if future studies included indices for depression, complicated grief, caregiver burnout, anxiety disorder, and substance abuse so that the contributions of these variables could be evaluated.

The study relied on several patient safety organizations for recruitment of family member participants. Unique characteristics of these organizations may assist family members in coping in the aftermath of the medical error. A revised study should include measures to evaluate how the organization supports family members as well as the efficacy of the various outreach programs implemented by each organization. Equally, the family members seeking support from a patient safety organization may do so because they have experienced an especially egregious or difficult to bear medical error injury of a loved one. If so, this factor may partially explain the high rates of PTSD in this population. For these reasons, studies examining the response of family members reporting a loved one injured by medical error and not seeking affiliation with patient safety organizations must be completed and the findings from this study should not be generalized to the larger population.

In addition, in some family member reports, it was evident that the medical error experience did not yield long-term psychological harm. A small number of family members noted personal growth experiences. So, future studies of the impact of medical error should be informed by studies

of resilience and posttraumatic growth in other populations that are exposed to traumatic events (Bonanno, Papa, Moskowitz, & Folkman, 2005). Such knowledge could inform the creation of effective support services for family.

Despite these potential limitations, findings from this study begin the first steps in a long overdue investigation of the impact of medical error in the family members of the injured. In addition, findings from this study contribute to the growing body of research that promotes honest and open communication of information in medical care, increased quality of medical care for all populations, decreased incidence of harm in the delivery of medical care, and appropriate support for individuals harmed by medical error incidents: the patient, the healthcare professional, and the family members.

In conclusion, a medical error experience is an extraordinary event. Unfortunately, this extraordinary event occurs with alarming frequency. Unless healthcare professionals are able to understand the impact from the family members' point of view, it will be difficult to find an appropriate and ethical response to a medical error event. Consider how a reasonable estimate of 196,000 family members with loved ones seriously injured by medical error can be achieved by taking the Institute of Medicine's figure (98,000 patient deaths in hospitals annually; Kohn, 2000, p. 26) and multiplying the number of patient deaths by two family members. Viewed from this perspective, the psychological, social, moral, and personal consequences of the ordeal are significant.

Afterword

My mother suffered and died from alarmingly poor medical care. Her physicians had knowledge of serious error and did not inform her or her family members. No steps were taken to prevent similar harm from happening to others. Moreover, evidence indicated that her physicians did not disclose the errors because of malpractice concerns. These truths were difficult to accept.

This research grew out of my efforts to understand the tragedy of medical error, my need to help my family cope with the aftermath of medical error injury to our loved one, my inability to silently accept the hundreds of thousands of lives lost to medical error as insignificant, and my desire to help the countless numbers of individuals that find the impact of medical error a difficult burden to bear.

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