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Long-term Impacts Faced by Patients and Families after Harmful Healthcare Events

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Abstract

Background—Patients and families report suffering a multitude of harms from medical errors resulting in physical, emotional and financial hardships. Little is known about the duration and nature of these harms and the type of support needed to promote patient and family healing after such events. We sought to describe the long-term impacts reported by patients and family members who experienced harmful medical events 5 or more years ago.

Methods—We performed a content analysis on 32 interviews originally conducted with 72 patients or family members about their views of the factors contributing to their self-reported harmful event. Interviews selected occurred 5 or more years after the harmful event and were grouped by time since event, 5–9 years (22 interviews) or 10 or more years (10 interviews)

for analysis. We analyzed these interviews targeting spontaneous references of ongoing impacts experienced by the participants.

Results—Participants collectively described four long-term impacts: psychological, social/behavioral, physical, and financial. A majority cited psychological impacts with half reporting ongoing anger and vivid memories. Over half reported ongoing physical impacts and one-third experienced ongoing financial impacts. Long-term social and behavioral impacts such as alterations in lifestyle, self-identity, and healthcare seeking behaviors were the most highly reported.

Conclusions—These patients and families suffered many profound long-term impacts after their harmful medical event. For some, these impacts evolved into secondary harms ongoing 10 years and more after the event. Our results draw attention to the persistent impacts patients and families may experience long after harmful events and the need for future research to understand and support affected patients and families.

Keywords

medical errors; harm; healing; communication; patient/family

INTRODUCTION

Harmful events in healthcare settings can be life-changing, and can lead patients and families to suffer physical, emotional, psychological, social, and financial impacts (1–6). With the national spread of Communication and Resolution Programs (CRPs), some health care organizations have become more open and transparent about medical errors as they strive to better support patients, families, and clinicians in the immediate aftermath of harmful events (7–9). Yet little is known about the types of long-term impacts (LTI) that patients/families experience years after the event has occurred, and how these might affect their future healthcare needs and behaviors. By better understanding the full range of patients' and families' experiences, health care organizations can provide more holistic follow-up care and treatment, and strengthen disclosure and resolution programs to mitigate some of these negative impacts and promote the healing process (10,11).

Patients and families experience harm from the harmful event itself but they can also experience secondary harms from how the event was handled (12–14). Yet systematic data concerning the types and duration of these secondary harms affecting patients and families after harmful events are sparse (1–2) and do not distinguish between early, late or ongoing long-term impacts. The lack of understanding about the long-term impacts patients and families experience after harmful healthcare events is likely due to several factors. First, the patient safety movement is still burgeoning. Just in the last fifteen years have hospitals begun to openly acknowledge the acute impacts of medical errors on patients and families, and few if any programs followed patients longitudinally. Second, the traditional hospital risk management approach to deny and defend errors is just beginning to change as more organizations adopt communication and resolution programs to improve safety and learn from errors (10, 11). Third, healthcare organizations may have difficulty routinely identifying and maintaining contact with harmed patients and families due to liability

concerns, inhibiting systematic follow-up and awareness of long-term impacts (10). Fourth, complex and competing demands within health care organizations may impede efforts to financially and psychologically support harmed patients and families (9). For some patients, such as those who develop post-traumatic stress disorder, these long-term care needs may be very time-consuming and expensive. Fifth, there may be an overly optimistic belief that the emotional harms will resolve after a few months, and a false perception that they are not as “important” as physical harms, although data suggest the opposite (1,15).

To address this lack of knowledge about the long-term impacts, including emotional and psychological sequelae of harmful events on patients and families we performed a secondary content analysis of interviews conducted with patients/families who self-reported harmful events during their healthcare. Our aims were to 1) identify the long-term impacts that patients and families spontaneously reported during interviews about their harmful event and 2) identify contributing actions (or inactions) from the hospital or health care provider that influenced these long-term impacts. This knowledge may help health care organizations provide more effective support for patients and families and shed light on the length of time such support may be required.

METHODS

Participants

This exploratory investigation was part of a larger study that sought to examine if patients/families could identify specific types of contributing factors that they felt led to their harmful event (16). Institutional Review Board approval was obtained prior to study initiation. We reached out to 3 large healthcare systems in Texas and three nonprofit patient advocacy organizations (Consumers Union, Connecticut Center for Patient Safety, and ProPublica) to invite patients to voluntarily participate via their own email listserv, website advertisement, and mailings. Volunteers were eligible if they reported ever having experienced a harmful event, were notified of the event (experienced a disclosure conversation), were English and/or Spanish speaking and were not involved in active litigation processes pertaining to the harmful event. Family members or significant others who were present with the patient during the time of event were also invited to participate in interviews on behalf of their loved ones and/or for patients under 18 years of age. Between August 2012 and July 2014, a sample of seventy-two eligible patients and families participated in individual telephone interviews lasting 60–90 minutes. Participants were asked to describe their experience and discuss factors which they thought may have contributed to the event and their recommendations to improve the patient experience after harmful events. Interviews were audio recorded, transcribed, cleaned of identifiable information from the written text and validated against the audio recording to ensure accuracy. A more detailed description of the methods is outlined in a previous paper (16).

In the original study interviews, many participants shared they were experiencing ongoing harms despite the fact that there were no interview probes or questions asking participants about long-term effects they experienced from their harmful events. For this study, we sought to describe the long-term effects these participants spontaneously reported during their interviews. We categorized the 72 interviews into groups based on the years that had

transpired from the event: less than 5 years group (n= 40), 5–9 years group (n=22) and 10 years or more group (n=10). We defined “long-term” as events occurring 5 years or more previously, therefore we included only the 32 interviews from latter two groups in our analysis.

Analysis

To conduct a thematic content qualitative analysis, we developed an initial coding scheme by selecting 3 of the 32 interview transcripts to be individually coded by three researchers (AOA, EWS, and MJO) using ATLAS.ti v.7, a qualitative analysis software for data management. Each researcher developed a separate list of codes and conferred with a fourth researcher (EJT) to reach agreement about a final code list. Code definitions and coding instructions were agreed upon for use in the remaining interview transcripts. Two researchers (AOA and EWS) coded the 29 interview transcripts independently meeting weekly to verify agreement in coding of the text and emerging themes within each narrative. Throughout analysis, new codes were iteratively developed as researchers identified more precise interpretation of meaningful text within the narratives. Coding discrepancies were discussed with MJO and EJT until a consensus was reached and a final (coded) transcript was documented and saved. A thematic analysis of the coded data was conducted by grouping codes into like categories or themes (17). Three researchers (AOA, EWS, and MJO) met weekly to discuss emergent findings. Upon consensus, data was reviewed with EJT to reach agreement of the substantive themes and quotes illustrated in the data. To analyze the differences of spontaneous responses between groups we quantified the responses by code and by group (5–9 years post-event vs 10+ years post-event).

RESULTS

Participants were predominantly recruited from consumer advocacy groups, comprised of mainly women (between ages 46–64), and identified as Caucasian (Table 1). Most participants (59%) were patients reporting a harmful event while the remaining participants were loved ones speaking on behalf of their children, parents, and spouses. Of these, 69% of participants described experiences related to events that transpired 5–9 years prior to the interview and 31% of participants described reactions to harmful events 10+ years prior (Table 1). A majority (72%) of the harmful events occurred within inpatient settings and 87% were classified by our research team as serious with 31% resulting in death, and 56% leading to permanent harm (Table 2).

Long-Term Impacts

We found four common themes among long-term impacts described by patients and families who experienced harmful events 5 or more years previously: psychological, social or behavioral, financial and physical (Table 3). Almost all (94%) of the participants spontaneously described experiencing one or more of these long-term impacts. Two participants, in the 5–9 year group, did not mention any ongoing harms in the interview. There was little difference in the broad categories of long-term impacts between participants in 5–9 year versus 10+ year groups. Although “altered life/view of self” and “altered healthcare seeking behaviors” were most prominent in the 10+ year group, whereas “sharing

their experience publicly, anger, vivid memories, and loss of trust” were more prevalent in the 5–9 year group (Table 4). Social/behavioral impacts were the most prevalent and nearly universal, followed by psychological impacts physical impacts and financial impacts. Examples of representative quotes for each category are found within the results or in Table 5.

Social/Behavioral Impacts

Sharing Their Experience Publicly—For a majority of patients and families (66%) recruited from healthcare systems and consumer groups, the harmful event ignited a desire to use their experiences to help prevent similar events from occurring to future patients and to improve hospital practices and accountability. Their efforts included telling their stories informally or at public speaking events, testifying to Congress, participating in volunteer work, support groups, and advocacy groups, writing for newspapers, editorials, online forums, publishing books and participating or conducting their own research.

“I wanted to tell my story. My whole goal, since I can’t do research anymore, since I can’t teach anymore, and since I know I am dying, is to save the lives of other people. That’s all I care about.” (Participant 65)

Altered Life/View of Self—Over half (59%) of these patients and families explained dramatic changes in their lives and their view of themselves—mainly due to the physical ramifications and emotional stressors they were still dealing with years after the event. They described how their lives would never be the same due to the loss of career, family business or the ability to do activities they once enjoyed. Consequently, they identified themselves as “victims” and “survivors” and they felt it was difficult for others to understand and empathize with their experience.

Altered Healthcare Seeking Behaviors—One-third of the participants felt the event caused them to change their healthcare seeking behaviors. Patients/families vocalized their refusal to seek future care in hospitals as a result of the harmful event and the way the hospital inadequately communicated with them, lacked concern for their wellbeing, and refused to apologize or acknowledge the medical error that occurred.

“Now I have this big fear of going to a hospital. I’d rather croak in my own bed than go to a hospital. After all this stuff that I saw.” (Participant 25)

For some patients/families the event caused them to become more inquisitive and more mindful of obtaining medical records for their own protection. They were more likely to advocate for themselves by speaking up about healthcare concerns, obtaining second opinions, and researching healthcare information on their own.

Psychological Impacts

Anger—Half (50%) of the patients and families expressed ongoing feelings of anger and frustration as they described the way the hospital handled their situation. Patients and families were angered that providers/hospitals did not acknowledge and/or apologize for their errors and sometimes went to extreme lengths to cover up their mistakes and/or cast

blame on the patient/families. Often times, patients/families felt “lied to” or ignored when inquiring about their harmful event. One patient shared,

“I think this is a perfect setting where somebody from the hospital administration should have responded to my demands to talk to someone there, rather than ignore me. Because here it is six years, seven years later. And I’m still angry about it”.
(Participant 57)

As their efforts to speak with hospital administration were rejected, patients and families were left speculating and confused about the causes leading to their event. Patients/families also spoke heatedly about receiving incomplete/inaccurate medical records or being denied access to their medical records upon demand.

Loss of Trust in Healthcare—Patients and families found themselves feeling betrayed and losing trust in providers and the healthcare system. They felt the hospital representatives exhibited “arrogance” and “deception” when they requested medical records or other information pertaining to their event. Patients and families felt a lack of concern for their wellbeing from their healthcare providers especially in the absence of an apology and acknowledgment of the medical error that occurred. For half of these participants, this ignited a repulsion and refusal to visit hospitals as a result of the harmful event as this patient states:

“...I used to think hospitals were a place that you went to get adequate care and you got better and you came home. I didn’t realize you could go in with one thing, and then wind up dead from another and it terrifies me.” (Participant 25)

Vivid Memories—Patients and families used strong language to illustrate vivid memories that remained with them long after experiencing their harmful event. Participants used words such as “nightmare”, “hell”, “terrifying”, “horrificing”, and “the worst week of my life” to describe what happened to them, portraying the gravity of their experience and the intense emotions that lingered on years after the event.

Self-Blame—Patients and families recalled having a sense that something was not right, but did not trust their “first instincts” about their care, and instead overruled their own judgment with that of the physicians’ orders. They related this from being implicitly trusting of the clinicians or feeling that as lay persons, they were not knowledgeable or comfortable enough to vocalize their opinions. These participants expressed ongoing regret in wishing they had advocated for themselves or their family member asked to see their medical record or investigated more information about the doctor or hospital.

Grief—Patients and families emphasized feelings of grief, sadness and suffering as a result of the harmful event they experienced years ago. They felt helplessness and abandonment from the healthcare system. Recounting their story intensified their feelings of grief and for some moved them to tears.

Psychological Scars—A third (34%) of patients and families described long-term effects of traumatization and “psychological scars,” depression, paranoia, suicidal thoughts, and

need for psychotherapy. These patients/families were still bothered by the unknown causes of the event, had difficulty with forgiveness and were not able to forget the hospital's behavior toward them years after the event.

“The minute I walk into that door and say, “You hurt me and let me just talk about it.” ...they would not talk to me... they didn't care that they had hurt me. Nobody did. The thing is I am one of the luckier ones...I'm able to at least still have a life. I wasn't paralyzed. I wasn't maimed... all of us who have been a victim or a survivor of patient harm, all share the same psychological scars. This has been about, I don't know, five years ago, I guess. I mean I've been suicidal over this.” (Participant 71)

Physical Impacts

Sixty-six percent of patients and families suffered from lasting physical injuries as a result of their harmful event. Various types of long-term physical impacts were experienced which led to debilitating circumstances and permanent damage lasting years after the initial physical harm occurred. The long-term physical impairments included dysfunction or loss of limbs, organs, or senses. Patients with long-term physical impacts required multiple surgeries and lifelong treatments such as rehabilitation, medication, and/or therapy in order to cope with their physical ailments.

“As an outcome of that [surgical error]... I was totally and irreversibly blind very early into the first recovery period after the first morning surgery. And to date, I am 100% blind in both eyes... I have no light perception.” (Participant 22)

Financial Impacts

Thirty-one percent of patients/families were still burdened by financial issues long after their event. Financial impacts were inter-related with physical impacts, where physical disabilities led to lost jobs and/or health insurance, accumulation of expensive medical bills, and reliance on Medicaid/Medicare services. Disabled patients reported needing costly long-term care including rehabilitation, extra treatment (procedures/surgeries), medications and/or specialized equipment and supplies.

“I'm in physical therapy the rest of my life because of how he butchered everything up. It threw my whole body off, and so it's costing a fortune... I've spend thousands of dollars and met with experts and specialists.” (Participant 34)

Most participants sought compensation from the hospital when the family's income was impacted from the patient losing their job or passing away.

DISCUSSION

Many healthcare systems are implementing programs that promote communication and “resolution” with patients and families after harmful events (9). But for the individuals we interviewed, the notion of “resolution” was elusive, as they reported profound and sobering psychological, social, behavioral, financial and physical sequelae lasting for years after their harmful event. They emphasized that lack of transparency, absence of error acknowledgment, and ineffective communication precipitated their strong emotions and

contributed to the long-term impacts. The persistence of anger, grief, and self-blame by patients and families more than a decade after the event suggests that exploring and unpacking patient and family feelings should be a routine part of disclosure training and communication after harmful events (5–7). If found to be generalizable in larger studies of more diverse patients and families, our results signal the need for healthcare organizations to learn more about the long-term consequences of harmful medical events and to better support patients and families over time.

Of significant concern were the “psychological scars” reported by patients and family members such as anxiety, depression, nightmares, negative or distorted beliefs, and alarmingly, even PTSD and suicidal thoughts, that persisted for over a decade in a third of the participants. These PTSD-related symptoms (18, 19) impacted interpersonal, social, and occupational aspects of their lives. Understanding the genesis of psychological harm after harmful events warrants more exploration into what constitutes harm, how patients and family members perceive harm and what causes the harm. From this explorative study, we propose a conceptual model depicting development of secondary harms from harmful events (Figure 1). Future research is needed to validate and refine the model, and to determine whether/how secondary harms may be mediated by the response of the healthcare provider and organization.

Our data suggests that some harmed patients and families may require active outreach before returning to the health care center or receiving any type of medical care again. Health care organizations may consider systems to flag the records of patients and families harmed by care so that they can be identified and supported when they return, or connected to care elsewhere. Given the prevalence of medical errors in the US (20), there may be a role for clinicians to routinely ask patients about past personal or family-related medical harms as part of the history-taking in health care encounters to preemptively support patients who may harbor secondary psychological effects from post-traumatic harms. More research is needed to evaluate the costs and benefits of this type of endeavor to promote improved patient outcomes.

For some patients and family members, sharing their experience publicly was a positive coping mechanism in response to their harmful event. Although likely biased by our recruitment from advocacy groups, patients and families are motivated to share their story because of a desire to prevent future harms and promote post-event learning with healthcare providers (6, 10, 21). Physicians who made errors report telling their story during a debriefing with a qualified professional provided a similar positive coping mechanism in their healing (22). Debriefings engage participants in expressing their feelings about the event, assess for the presence of psychological trauma (23) and support their psychological healing. Such programs could be structured to help harmed patients and families identify and provide tangible support for their emotional and healthcare needs (24), signal strong institutional concern for their well-being (25) and provide opportunities for purposeful post-event learning.

There were six factors limiting the generalizability of this study. First, a high proportion of participants were recruited from advocacy groups, 2) patients involved in active litigation

were excluded, 3) a high number of respondents were women, 4) due to recruitment methods we are not able to report on the response rate of those who chose to participate in the original study, 5) our results reflect patients' perceptions of the event and were not corroborated by other stakeholders and 6) there is wide heterogeneity among participants and their errors, although the majority reported high severity events resulting in permanent disability or death. Long-term impacts may differ based on intrinsic patient characteristics, type and severity of error or setting in which the error occurred, healthcare organization reactions (such as degree of transparency and quality of communication or participation in a communication and resolution program) and whether litigation was pursued, all of which merit further research. Additional inquiry into the relationships between litigation and event severity, event severity and long-term impacts and the effect of communication and resolution program on each of these relationships is also needed. Due to the original study aims, these participants were not specifically asked to describe long-term impacts related to their harmful event. Therefore, the data may not have captured all of the participants' post-event experiences, and the frequency and types of long-term harms may be greater than we report here.

Despite these important limitations, our exploratory study is one of the first to address the difficult topic of patient and family experiences of harm events, as risk management concerns have generally prevented these types of studies in the past. Our findings are sobering and suggest a call to action and the need for future research. Uncertainty exists as to whether the long-term impacts experienced by patients and families were influenced solely by inadequate communication and support with the healthcare system, or if other unrelated factors contributed over time. Epidemiological studies are needed to fully examine the incidence and prevalence of traumatic impacts to patients and their family after medical errors, their duration, how patients' needs change over time and the factors influencing the likelihood that patients/families will experience long-term impacts after medical errors. Elucidating what precipitates PTSD-like reactions in patients and families after harmful events would enable healthcare organizations to proactively identify patients/families at risk and support them earlier in their healing process. A better understanding of these dynamics could improve communication strategies and long-term support for patients/families.

CONCLUSION

In addition to the original physical injury occurring from harmful events, patients and families can continue to experience long-term psychological, social/behavioral, financial and physical harms even a decade or more after the event. Health organizations need to better understand the potential impacts to patients and families caused from the trauma of harmful events and be willing to support their patients over the longer term. We recommend additional research in understanding and supporting patients and families after harmful events.

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Figure 1.
Conceptual Model of Secondary Harms to Patients/Family After Medical Errors

Table 1

Participant Demographics

Participant Characteristics	Patients	Family members	Total
Gender of Informant			
Female	16	10	26 (81%)
Male	3	3	6 (19%)
Age of Informant at time of interview			
31–45 years	1	3	4 (13%)
46–64 years	15	8	23 (72%)
65–75 years	2	1	3 (9%)
76–85 years	1	1	2 (6%)
Race of Informant			
White/Caucasian	16	10	26 (81%)
Black/African American	1	1	2 (6%)
Hispanic	0	0	0 (0%)
Asian	0	1	1 (3%)
Other	1	1	2 (6%)
Chose not to answer	1	0	1 (3%)
Type of Referral			
Consumer Interest Group	17	12	29 (91%)
Hospitals	2	1	3 (9%)
Time Between Event and Interview			
10+ years	7	3	10 (31%)
5–9 years	12	10	22 (69%)

Table 2

Event Characteristics

Event Characteristics	Number	%
Gender of the Patient Involved		
Female	25	78%
Male	7	22%
Age of Patient at Time of Event		
< 18 years	3	9%
18–30 years	0	0%
31–45 years	10	31%
46–64 years	10	31%
65–75 years	2	6%
76–85 years	1	3%
86+ years	6	19%
Type of Initial Event		
Diagnostic Error	5	16%
Fall	1	3%
Inappropriate Therapy/Care	2	6%
Infection	11	34%
Medication Error	5	16%
Procedure Error	3	9%
Surgical Error	5	16%
Initial Event Setting		
Inpatient	23	72%
Outpatient	9	28%
Level of Harm		
Permanent Harm	18	56%
Death	10	31%
Temporary Harm	4	13%

Table 3

Definitions of “Long-Term” Impacts Coding Terms Used For Analysis

Term	Definition
Social/Behavioral Impact	Any references to how the event changed the way the participant behaved or impacted their social or family life (ie: no longer afraid to speak up; has to drive hours to seek medical care, wrote a book to share story, etc.)
Psychological Impact	Any references to how the event changed the way the patient/family thinks or feels (ie: lost trust in provider, still angry, self-blame, etc.)
Physical Impact	Any references to prolonged care or physical state experienced subsequent to event by the patient/family (ie: disability, rehabilitation, continuous meds, etc.)
Financial Impact	Any references to prolonged financial issues experienced subsequent to event by the patient/family (ie: medical bills, losing job, etc.)

Table 4

Long-Term Impacts Reported By Patients/Families

	5–9 year group n=22 (69%)	10+ year group n=10 (31%)	TOTALS n=32 (100%)
Social/Behavioral Impacts	20 (91%)	9 (90%)	29 (91%)
Sharing Their Experience Publicly	16 (73%)	5 (50%)	21 (66%)
Altered Life/View Of Self	12 (55%)	7 (70%)	19 (59%)
Altered Healthcare Seeking Behaviors	6 (27%)	4 (40%)	10 (31%)
Psychological Impacts	16 (73%)	7 (70%)	23 (72%)
Anger	12 (55%)	4 (40%)	16 (50%)
Vivid Memories	13 (59%)	4 (40%)	17 (53%)
Self-Blame	8 (36%)	4 (40%)	12 (38%)
Grief	8 (36%)	3 (30%)	11 (34%)
Loss Of Trust In Healthcare	13 (59%)	3 (30%)	16 (50%)
Psychological scars (depression, suicidal thoughts, paranoia, and Posttraumatic Stress Disorder (PTSD))	7 (32%)	4 (40%)	11 (34%)
Physical Impacts	14 (64%)	7 (70%)	21 (66%)
Financial Impacts	7 (32%)	3 (30%)	10 (31%)

Table 5

Representative Quotes of Long-Term Impacts

SOCIAL/BEHAVIORAL IMPACTS	
Sharing Their Experience Publicly	<ul style="list-style-type: none"> <i>I now go around the country teaching at hospitals and hospital organizations and APIC (Association of Professionals in Infection Control)...I'm going around the country trying to clean up healthcare, and yet my hospital has not reached out to me. (Participant 6)</i>
Altered Life/View of Self	<ul style="list-style-type: none"> <i>Well, I've been telling you. That has cost me my whole life. It has cost me the rest of my life. [But] I'm still living...still continuing. (Participant 30)</i> <i>I'm an educational researcher. I was. Now I can't do very much about anything. I have a lot of very non-functional days. I'm classified as permanently disabled... It has limited my life. (Participant 65)</i>
Altered Healthcare Seeking Behaviors	<ul style="list-style-type: none"> <i>And when you're very sick in the hospital, you're afraid to speak up initially. I'm not anymore, because I've been through so much that I certainly will tell them everything I need to say, and they better do it as long as I'm conscious and aware of what's going on. (Participant 47)</i>
PSYCHOLOGICAL IMPACTS	
Anger	<ul style="list-style-type: none"> <i>But what turns you into the bitter, angry patient is the fact that you can't get answers...or there are key pieces missing out of your medical record...or things are incorrect...or the hospital won't talk to you. Or you start to uncover lies that have been told to you. (Participant 6)</i> <i>That sends a very bad message to the people who are now having their lives crucified because of this guy's arrogance. They all put their lives and their careers on the line to cover up for this guy's arrogance because he wouldn't dare admit he had made a mistake. (Participant 49)</i>
Vivid Memories	<ul style="list-style-type: none"> <i>It was almost like this bad movie. They surrounded me in the entryway, in the lobby there, and started arguing with me about why I shouldn't want the records, which is my right as a consumer to see the records. (Participant 69)</i> <i>As I said, I was in intractable pain that was not dealt with. They forced a breathing tube down my throat while I was wide-awake. And I actually thought it was going to kill me. It was just such a nightmare. The whole situation was such a nightmare, which has left me with Post Traumatic Stress Disorder because I can't forget everything that happened to me there. (Participant 47)</i>
Loss of Trust in Healthcare	<ul style="list-style-type: none"> <i>It's left a lasting impact on me because I used to have a lot of confidence in our health care and now I don't have much at all. ...I'm even afraid if I ever have to go to a hospital, I'm going to be terrified. Because I used to think hospitals were a place that you went to get adequate care and you got better and you came home. I didn't realize you could go in with one thing, and then wind up dead from another and it terrifies me. (Participant 25)</i> <i>When we went in, things were just one after another...afterwards we learned there was deception, their arrogance, they were [not] communicative. It shattered my confidence and the image about the medical profession. (Participant 28)</i>
Grief	<ul style="list-style-type: none"> <i>The traumas that I've been through are really sad [crying]. If you stop and look at everything that happened to me over these years... I lost everything. I lost a career, a salary. Like I said I could have lost my kid. (Participant 71)</i> <i>The way I was treated by the doctor there, was atrocious. Nobody should ever be treated like I was treated there—often ignored. (Participant 47)</i>
Self-Blame	<ul style="list-style-type: none"> <i>And I wish I had listened to my inner voice. My inner voice was trying to tell me something wasn't right, but I silenced it because I had trusted this guy for 20 years. So, and he was a doctor. You know? He was the authority. (Participant 37)</i> <i>My mother I think will forever feel guilty for not feeling like she could say to this young doctor that was taking care of my grandfather, "Hey, you didn't wash your hands." But she didn't feel comfortable doing that because there's sort of a mystique around doctors. And she didn't feel comfortable. (Participant 52)</i>
Psychological Scars	<ul style="list-style-type: none"> <i>The minute I walk into that door and say, "You hurt me and let me just talk about it." ...they would not talk to me...they didn't care that they had hurt me. Nobody did. The thing is I am one of the luckier ones...I'm able to at least still have a</i>

life. I wasn't paralyzed. I wasn't maimed. I wasn't, you know, physical injured. But I think we all...all of us who have been a victim or a survivor of patient harm, all share the same psychological scars. This has been about, I don't know, five years ago, I guess. I mean I've been suicidal over this. (Participant 71)

PHYSICAL IMPACTS

- *As an outcome of that [surgical error], immediately all of the blood that was supposed to go through my entire body—all of the blood backed up above the heart and mostly into the brain. And that is where the damage was done. It was done in the occipital area of the brain... the blood went everywhere else, except into the optic nerves. And I was totally and irreversibly blind very early into the first recovery period after the first morning surgery. And to date, I am 100% blind in both eyes... I have no light perception. (Participant 22)*
- *I mean, the other ovary and my uterus were perfectly healthy. There was no reason to even touch them. My gynecologist did a frozen section in the operating room of the cyst, and it was benign... So even though it was benign...he removed both of my ovaries and my uterus and there was nothing wrong with the other ovary or my uterus... he should have only removed the cyst. The ovaries produce hormones into a woman's 80s. So, it took me from being 49 to 80-plus. (Participant 37)*

FINANCIAL IMPACTS

- *I was disabled from the beginning. I went back to work. I tried for the first six months, because I was being promoted to vice president. And I didn't want to lose my job. So I really tried hard to go back to work. But I just was too sick... And then within four years or so, I ended up in a wheelchair... I lost everything. I lost a six-figure job. (Participant 44)*