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Harm to Healing – Partnering with Patients Who Have Been Harmed

M. Trew, S. Nettleton and W. Flemons

Safe care…accepting no less
Soins sécuritaires…n'acceptons rien de moins

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1 - Background Considerations

The safety of patients using the healthcare system will always require close attention due to the very nature and complexity of healthcare. While patient safety is more widely discussed and a higher organizational priority than a decade ago, a substantial number of patients continue to be harmed while receiving care[3].

Harm in healthcare is an international phenomenon with dozens of organizations and associations around the world (i.e., the World Health Care Organization, the Institute of Medicine, the Institute for Healthcare Improvement, the Canadian Patient Safety Institute, and Patients for Patient Safety Canada to name but a few) learning and sharing new knowledge to mitigate harm to patients. Many fields of study including human factors engineering, organizational design, and organizational functions such as communication, teamwork, leadership and culture are helping to enrich the understanding of patient safety incidents and harm [2, 25, 26, 27, 37, 46, 47, 60, 63]. The intent of this work and report is to stimulate learning and knowledge in another relatively new and important area of patient safety – the engagement and partnering of patients and/or their families who have been harmed in healthcare to help make the system safer.

Several healthcare organizations that have become leaders in patient safety have found that partnering with patients and families who have been harmed provides important and often overlooked opportunities to make care safer. The Institute of Medicine's report of 1999, "To Err is Human" [27] recommended the involvement of consumers in patient safety efforts. In the years following this report more organizations like the Dana Farber Cancer Institute of Boston, Massachusetts have begun collaborating with patients and families. These innovating organizations have moved to include the patient/family perspective in many of their systems level quality and safety improvement initiatives [8, 10, 11, 29, 30]. Often, this work began after an open acknowledgment was made by the organization that harm (and generally severe or fatal harm to one or more patients) had occurred. These organizations accepted accountability for the harm. They understood that apologies and support to those who had been impacted were needed. They met with the patients/families and listened to their perspective. They undertook reviews and investigations to find out what had happened. They looked beyond the individuals (health professionals and staff) who were directly involved and examined system contributing factors. They heard and learned from others who had experience in system safety. They had a strong desire to improve, to do better. These leaders were open to change and understood that they had to help create a different culture in their organization. Engagement - with staff, leaders, health professionals, the patients/families who had been directly impacted, and the public - become a central part of their patient safety strategy.

While many healthcare organizations are starting to consider different approaches to patient engagement, the involvement of those who have experienced harm within patient safety and improvement initiatives is still relatively new. Consideration of possible risks and costs to those involved including the patients/families, healthcare providers and leaders, as well as the healthcare organization as a whole, are often deterrents for those contemplating this type of engagement [52, 59]. When viewed alongside of the possible benefits, the risks and potential costs may seem too high, dissuading those with little experience in this area. These risks and benefits may include the following:

Potential Risks / Costs

- Increased emotional turmoil (e.g., anger, blame, etc.) for the patient/family
- Increased emotional turmoil (e.g., anger, blame, etc.) for the healthcare provider(s), leaders involved
- Decreased trust in specific healthcare providers, staff, leaders
- Increased fear by the patient/family of accessing and using the healthcare system
- Re-living the events with re-traumatization by those directly involved

- Damage to the reputation of the individuals directly involved
- Damage to the reputation of the organization
- Ongoing issues of trust and unrest in the workplace impacting morale, job satisfaction, recruitment / retention, and patient care
- Increased potential for litigation

Potential Benefits

- Opportunity to hear directly from and understand the perspective of the patient/family
- Opportunity to identify safety or quality improvements directly from the perspective of the patient/family
- Opportunity to develop solutions with a patient/family perspective
- Opportunity to promote communication and teamwork that includes participation from the patient/family
- Opportunity to enhance a culture of care which is more patient/family centred

Those with some experience with this type of collaboration have found that it can be extremely valuable and rewarding for all parties involved [23, 57, 59]. While the number of organizations and individuals in Canada engaging with patients/families in this manner may be relatively few, the study team believes that more are starting to understand how this type of collaboration can help shape the culture of care in a variety of settings, teams, and organizations. This benefit is especially evident in the areas of transparency, accountability, learning, improvement, and respect. As one family member put it, *"How the organization treats the few who have had the worst experiences, is an important reflection of the values of the whole".*

Given the risks and emotional context of this work, it is no surprise that the uptake by healthcare organizations of engagement with patients/families who have experienced harm has been relatively cautious and slow. While more accounts of individual patient/family experiences of harm are starting to emerge in the literature (e.g., in published journals, books, papers, documentaries, news stories, and on the internet in a variety of personal testimonies and tributes to loves ones), there is still much to learn about engagement in this area and how it can help re-build relationships and bring about positive outcomes [4, 18, 21, 22].

Many American and several Canadian led organizations are now dedicated to both the sharing of patient safety stories and facilitating work with healthcare organizations, providers and governments to bring about positive changes [9, 25, 26, 28, 30, 45]. Many of these important accounts of patient safety incidents focus on the patient/family's painful experiences of being left in the dark. Meaningful information and heartfelt apologies were not offered, leaving a sense of disrespect. Decisions and plans about what was going to be done to help prevent something similar from occurring again were either absent or not shared.

As collaboration with patients/families to focus on safety is still limited, there is a need to share experiences and understanding of the impact and dynamics of these relationships. Understanding can help make these initiatives work to make healthcare safer.

1.1 - Research Question

In 2009, a Calgary study team entered into a contract with the Canadian Patient Safety Institute (CPSI) to seek out, assess, and compile related research, approaches, and models to help inform the engagement process with patients/families who had been harmed while receiving care. This was specifically focused on the inclusion of patients/families in safety improvement initiatives. The study team focussed its work on the following:

1) An understanding of the continuum of healing for patients/families who had experienced harm from healthcare; and

2) *The development of a construct and framework to be considered when including patients/families as advisors in collaborative patient safety initiatives.*

The team agreed to conduct an initial face validation of the construct and framework with a number of patients/families and healthcare leaders who had recent experiences in collaborative patient safety initiatives.

CPSI provided a grant of $14,400 to fund costs associated with the study. This included assistance from a university researcher to help prepare the project plan and ethics proposal, along with dedicated time and expenses to conduct in-depth interviews and transcriptions. The study team members did not receive compensation from the grant for any of their time, work and contributions.

Like the Dana Farber Cancer Institute, the former Calgary Health Region's involvement with patients/ families who had been harmed, stemmed from a tragic patient safety incident which took place in 2004 [20]. As part of many improvements that were made following the ensuing investigations [23, 49], the Region began to place a greater emphasis on transparency, learning, quality and safety, education and communication, especially with those directly involved - the healthcare providers, leaders and the afflicted patients/families. In 2005, a small group of patients/families working closely with the Region encouraged the senior leadership team to support the formation of a volunteer advisory patient/family safety council. The Council was comprised of people with different types of patient safety experiences. Its purpose was to involve patients/families who had first-hand safety-related experiences to advise the organization on larger system safety improvements from this unique and important perspective [6]. Over the next four years the Region gained significant experience in this type of patient/family engagement. Collaboration with patients/families grew into other areas of quality improvement in the Region. Further study, analysis, and wider discussion of experiences in this area seemed logical next steps for the study team. These factors, combined with other national work being undertaken at the time by the patient led organization, Patients for Patient Safety Canada, highlighted a growing interest in this area.

1.2 – Starting Premises

At the outset, the study team articulated the purpose of its work - to help inform and advance new knowledge and experiences about patient/family engagement in patient safety.

The following premises helped guide the team in the development of the study:

- Engagement with patients/families in quality and safety improvement is important and meaningful;
- Including patients/family members who have experienced harm enables an important voice and perspective in improvement initiatives;
- Healthcare organizations have a responsibility to engage patients/families in a manner that is respectful of all who are involved;
- Patients/families who have been harmed in healthcare grieve in a way that is similar to, but distinct from other forms of loss;
- Healthcare providers and leaders in healthcare organizations may also go through a grieving process similar to what patients/families experience;
- Identifiable factors contribute to the successes or difficulties of engaging patients/families who have been harmed;
- Greater understanding of the harm to healing journey will assist patients/families, healthcare providers and leaders in these types of collaborative ventures;
- Second harm (Harm II) may be experienced by patients/family when the healthcare organization does not provide information with a reasonable explanation about the original harm in an open, timely and respectful manner.

1.3 – Working With Those Who Have Been Harmed

The incidence of being harmed while receiving healthcare in a hospital setting in Canada has been estimated to occur at a rate of approximately 7.5% [3]. As we are learning from a growing number of patients/families who are brave enough to share their harm related experiences, this can be life altering and devastating. Similar experiences are also coming to light and are being told by leaders and the healthcare providers directly involved in the safety incidents. While healthcare organizations and governments are more open when discussing patient safety issues and ways of mitigating harm than a decade ago, each new case of harm is its own unique tragedy. Patients, after all, come to the healthcare system and healthcare providers to be *healed* and not to be *harmed*.

1.4 - Understanding Harm, Human Factors and System Improvement

Like other sectors in society, imperfect systems in healthcare contribute to imperfect outcomes and outputs. In healthcare, these imperfect systems can translate into imperfect care and patient harm. This occurs because of human involvement and as a result of the complexity of the technology, systems, and interactions that are part of our world today. This is especially so in healthcare [59]. Errors are a part of all environments that involve humans because humans are fallible. Humans are subject to slips, lapses, trips or fumbles, can make knowledge or rule based mistakes, and can violate norms, standards, and rules [46]. In healthcare, errors can directly or indirectly cause harm. By redesigning and engineering safety into the culture of the organization, healthcare is made safer. Safety can be greatly enhanced by examining the human factors in the systems, especially situations that have the potential to cause harm. By looking carefully at hazards, defenses and losses, by understanding what is and isn't working to prevent harm, and by establishing barriers, alerts, and triggers which can help prevent erroneous processes before they occur, systems are made safer and harm to patients reduced. The continuous examination and learning from a systems and human factors perspective, that includes the experiences of those directly involved, along with others who have special training in this area, is fundamental to systems redesign and improvement of safety [36, 46, 60]. Learning and collaborative involvement includes the participation of all parties who are closest to and most impacted by these situations - the healthcare providers, quality and safety leaders, administrators, *and* the patients and their families [4, 10, 16, 44, 57].

For more than a decade, leading healthcare organizations such as the Dana Farber Cancer Institute in Boston, Massachusetts have been successfully collaborating with patients and family members in patient safety initiatives [10]. In the last five years, other healthcare organizations in the United States and Canada have started to follow suit [59]. This type of collaborative work is still relatively new and replete with risks, challenges and opportunities. Many are concerned that the involvement itself may cause further harm to the patient/family and to the healthcare providers, staff or administrators involved. Questions invariably emerge about the motivation for those wanting to be involved in this type of work. While patients/families may have doubts that healthcare organizations are really ready to listen, understand, and consider changes from their perspective, healthcare providers and leaders may also question the patient/family's ability to be able to see beyond their own suffering and pain and be able to focus on improvements at a systems level. Some have argued that healthcare organizations are only interested in engaging for the sake of appearances, a 'window dressing' in an attempt to 'look good' in the public's eyes. Others believe that this work is much too risky, complicated, emotional, and even unnecessary because healthcare leaders and providers are themselves patients/families and can provide the voice and experience of the patient/family. While more healthcare organizations are mindful of the need to include the patient/family perspective the inclusion of those who have experienced harm is still very much in its infancy.

With greater understanding of the factors that are associated with 'readiness' to be involved and more awareness of the journey from harm to healing, it is possible for healthcare organizations and their leaders and providers to successfully engage patients/families who have been harmed in important discussions of patient safety.

1.5 - Assessing the Fit and Readiness of the Partners

a – Personality / Skills / Experience

As in the first stages of forming any collaborative relationship, the partners often begin by reviewing the other's personal qualities to assess the 'fit' of the partner in this type of work and relationship. These initial assessments are often based on first impressions and considerations of personality, skills, and experience.

In the realm of patient safety and collaboration, both the patient/family and the healthcare providers/leaders are likely to assess the personality of the other party. When asked about this process, descriptors such as considerate, understanding, caring, genuine, honest, well intentioned, warm, or good listener are often used. Any of these might be indicative of a 'good fit' and help form the basis of a positive working relationship. On the other hand, descriptors such as cold, indifferent, self-centred, self-absorbed, insensitive, outspoken, overly talkative, very angry, agitated, fixated, stubborn etc., might suggest the opposite.

Assessing skills or relevant life and work experiences that would lend themselves to this work might include working with teams in collaborative ventures or experiences with large organizations. They might also include experiences or skills in healthcare, planning or policy development, quality improvement, program planning, communications, consultation, mediation, education, etc. All of these may have relevance in patient safety. Those with no previous experiences working with teams and especially in large, complex organizations and systems may find this type of collaborative advisory work to be very slow moving in bringing about change and thus frustrating. Patient/families and healthcare leaders and providers who are looking for quick and immediate action or instantaneous results may not be well suited to this work.

b - Motivation

Another important consideration of 'readiness' is understanding what might be the motivating or underlying drive and interest of the others' involvement in this work. Why do they want to do this? What might be behind their eagerness to participate? Patients/families will want to know why the organization is suddenly interested in hearing from them. Is the interest real and genuine or is it superficial? Is the organization really committed to this type of collaborative work? Is it part of the organization's vision, mission, and mandate? Is it endorsed and supported by the Chief Executive Officer or the Board of Directors? Has the organization allocated resources for this work? Are those who will be involved from the organization genuinely committed to this type of work? Any number of reasons to doubt the commitment of leaders and/or providers at the onset may indicate future challenges and difficulties.

Healthcare leaders and providers will likely want to know what is behind the patient/family's interest in participating. This is often the case when the harm has been more serious. While patients/families may be motivated by a genuine desire to see improvements, a small few may also be influenced by other factors such as personal ambition or an agenda which may conflict with this work. A win-lose approach on either side will not achieve collaboration.

c - The Right Time / Place to Participate - Understanding the Journey from Harm to Healing

One of the most critical assessments in determining 'readiness' for collaborative work is the consideration of time and place for participation. Questions including the following are often asked: 'Has enough time passed for the patient/family or for the person working in the organization to be involved in this type of work?' 'Is the harm too recent or too devastating?' 'Are there signs of moving through the process of grieving and coping which may help lead to recovery, healing and forgiveness?' 'Does readiness require forgiveness?'

The study team reviewed the literature in the areas of grief, bereavement [1, 12, 32, 34, 42, 48, 51, 53, 56, 58], and forgiveness [5, 13, 15, 19, 33, 35, 40]. The team concluded that *coping after harm in healthcare is a form of grieving and coping with loss*. In this way, the person who has been impacted by the harm mentally processes the loss associated with the harm in a way that is similar to other loss related experiences. In moving through the process of coping, some, but not all, will find themselves ‘sufficiently healed’ and will be able to collaborate from their perspective without being re-traumatized or further harmed by being part of this work.

In reviewing the literature as it relates to complicated grief, the study team believes that there will be some who will not be able to participate at the time, without being negatively impacted. Patients/families engaged too early in their recovery journey may unintentionally suffer further harm by being part of this collaborative work. Recovery and healing for these individuals, regardless of their wish to be involved, may take more time and further processing. Healthcare leaders or providers who have been directly involved in adverse events might also be negatively impacted by being involved in this type of work too early in their own recovery and healing journey. *While further harm for the individual* might occur in the form of re-traumatization, continued *harm for the organization* might take the form of lost hope for openness, trust and collaboration, resulting from recriminations by those directly impacted. In both of these situations, collaboration may be extremely difficult and result in limited success. Experiences with unsuccessful engagement may lead organizations and their leaders back to a more protective position where there is no engagement, or engagement exclusively with patients/families who have had only positive or no harm experiences. This in turn is often interpreted by the public, and patients/families as ‘window dressing’, ‘self-serving’, a ‘closed shop’, and reverting back to a mentality of ‘circling the wagons’.

In reviewing the literature on loss and complicated grief and its application to harm in healthcare, the study team developed the attached Harm to Healing Model (see Fig. 1: Healthcare Harm to Healing Model). The model outlines significant landmarks and opportunities that may influence and change an individual’s journey and recovery from harm. The critical junctures are noted below.

1.6 - Grief Process

The experience of grief and loss are universal. Early descriptions of grief in western society are found in the Christian Bible in Genesis and presumably in earlier oral traditions. In more recent years, authors such as Elizabeth Kubler-Ross [32] Colin Murray Parkes [41, 42], Jane Littlewood [34] and others [1, 5, 12, 13, 15, 19, 33, 35, 40, 48, 51, 53, 55, 56, 58] have described the process and experience of grief after the loss of a loved one. In reviewing these widely acclaimed works, the study team believes that many of the same processes outlined here are applicable and relevant to understanding *how a person deals with any significant loss* in their life, including harm from healthcare.

Elizabeth Kubler-Ross [32] describes the process of grief in five states or stages: *shock, anger, bargaining, depression,* and *acceptance*. Other authors [1, 34, 41, 48, 51, 53, 58] note a sense of *unreality* or *depersonalization,* a *yearning* which is observed along with processes of *disorganization and reorganization* of life.

a - Complicated Grief

Following a loss, many proceed through a path or a *trajectory of grief* before reaching a state of normalization. Some can move further into a deeper stage of grief and seemingly become ‘stuck’ in what is referred to as *complicated grief*. Here, individuals suffer not only from the original grief but also display signs of psychiatric conditions indicative of Major Depression or Post Traumatic Stress Disorder (PTSD) [14]. Between six to twelve months after a harmful incident, most individuals start to feel and see signs of recovery. Those who do not experience these signs of returning to ‘normal’ in day-to-day functioning may be experiencing *complicated grief*. It can be envisioned as two entangled threads of distress and disease – each of which further binds the other. Successful intervention generally involves more formal and professional treatment to address both elements.

Complicated grief may result from many contributing factors, including previous loss experiences, other current stressors, lack of supports, and so on [12, 34, 58]. In the context of harm in healthcare, the study team believes that some individuals may move into this area of *complicated grief*’ if there are *substantial* *unresolved issues* or where there is *unsupportive action on the part of individuals associated with the healthcare system and the harm experience.* Support for this understanding is also apparent in direct accounts from patients/families [5, 22].

b - Harm 2

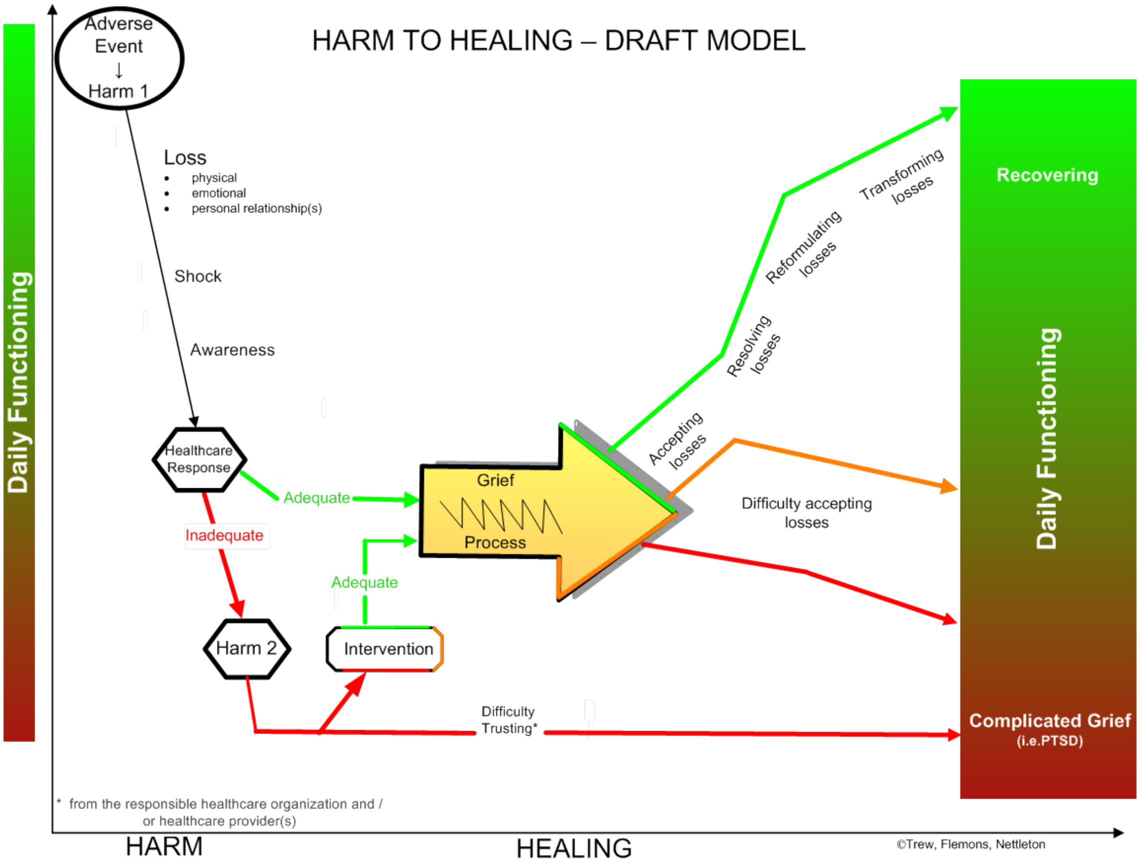
When the patient or family suffers from *unsupportive action on the part of individuals associated with the healthcare system and the harm experience,* the study team has termed this '*Harm 2' or 'Second Harm'*. This harm is a result of what the people in the healthcare experience or organization does or does not do to help the patient/family move towards a more normal cycle of grief and thus recover from the initial harm. Patients/families experiencing second harm, talk openly about feeling isolated after the harm. They speak about being shut out of meetings and discussions with those who were directly involved and who they believe have vital information that can help them understand what happened and why. They talk of questions that the organization with its leaders and providers will not answer. Many are quite frank about situations that they experienced as disrespectful; where no apologies were offered, where they see no consideration of their loss or the impact that the situation has had on their life [22, 18, 54]. This type of response by the healthcare organization is understood to cause further harm to the patient and family and could move the patient/family into *complicated grief.*

c - Coping Through Grief

In reviewing different models of grief and coping, the study team found that the *dual process* of Stroebe & Schut [56] resonated best in the context of harm in healthcare. In this model, one of the processes focuses on the loss, while the other revolves around coping through the restoration of daily functions. The study team believes that looking at grief in this manner helps to explain what are often thought to be contradictory behaviours that are seen in persons coping with grief. Sometimes grieving individuals seem to be obsessed in mourning. At other times, they remove themselves from anything that reminds them of the grief or grieving and try to 'get away from it all'. A degree of both approaches is thought to be required to return to a reasonably balanced pattern of daily life. Collaborating in safety while coping through grief may see the person highly engaged at one point while needing distance from this work at another point in time.

Losses to a patient/family in the context of harm in healthcare may include loss of *time*, loss of *trust in the people providing or in charge of the care,* loss of *functioning,* loss of *future expectations* of good health, abilities etc. In situations where the harm is fatal, *loss of a life, loss of a loved one and their continuing relationship* with the deceased is the basis of bereavement. Whatever the loss, it needs to be incorporated into the new pattern of everyday life.

1.7 - Harm to Healing: A Draft Model (Fig. 1 – Initial Model)



The diagram above outlines the original model as developed by the study team. It was based on the literature review of grief and descriptions in the literature of patient/family experiences in healthcare harm journeys. The model was shared with a group of participants who were interviewed as part of the study. Based on the comments received by the participants, the study team made further changes to the model. These modifications are displayed in Figure 2: Healthcare Harm to Healing Model.

The model is depicted as a pathway from harm to healing. It begins with the adverse event and the first harm, *Harm 1*. Losses associated with the first harm are depicted as being either physical, emotional and/or relationship in nature.

Those experiencing the harm often find themselves initially in a state of *shock.* This state is generally followed by a growing sense of *awareness* of the reality of what has occurred and the loss or losses involved. It is generally at this point, that the healthcare organization/provider responds to the person who has been impacted. If the response is perceived as '*adequate' by the patient/family*, the person will likely proceed through a relatively 'normal' process of *grief.* As noted earlier, this journey to restoration of functioning often includes a degree of *acceptance* of the loss(es), some form of *resolution* of the loss(es), an internal *reformulation* of the loss(es), followed by a *transformation* of the loss(es) – and even possibly a transformation within the person themself [19, 40, 50].

The study team believes that what might constitute an 'adequate' response to the harm for the patient/family would include things such as timely communication, demonstration of compassion and support, an appropriate apology, and disclosure. The team notes that what is ‘adequate’ for one patient/family member might be quite different for another. Also what might be ‘adequate’ to someone at one point in time might not be ‘adequate’ at a later point in time.

The team also concluded that if the response was perceived as being ‘not adequate’ it could lead to another form of harm, *Harm 2*, as described above. Without intervention and treatment, some affected individuals might become ‘stuck’ in a more complicated form of grief [12, 34, 58], *complicated grief*.

The study team came to understand that *Harm 2* was often experienced as a feeling of betrayal by the patient/family. Some have described it as being even more devastating than the first harm. If left unresolved and unaddressed, the person affected might become even more distrustful of the healthcare system [21]. Active intervention from healthcare providers or leaders in the system in the form of an appropriate expression of apology and disclosure may help the person return to a more ‘normal’ trajectory of grieving and recovery [12, 34, 58].

One important pathway outlined in the model involves situations where the response to the harm may initially be ‘*inadequate*’ but after *‘interventions’* are made and put into place (e.g., meetings with the patients/family, information or follow-up provided etc.,), the situation is improved for the patient/family. The impact of this action and the improved response may help to move the patient/family back onto a more normal path of grieving and recovery.

2 - Methodology

The study team used a three staged approach in developing the model and key concepts:

1) review of the literature as it pertained to grief, bereavement and forgiveness as it might relate to harm from healthcare;
2) discussions among members of the study team and with field and knowledge experts to help formulate an early model of the harm to healing journey and key concepts;
3) testing of the model and key concepts with other field and knowledge experts and with patients/ families who had experienced harm and had recently collaborated with healthcare organizations.

An extensive literature review provided background and context for both development of the model and key concepts. The literature review included a search on published and unpublished literature (i.e., journal articles, books, and grey literature). Key search items included: grief, harm, healing, forgiveness, and patient participation / patient collaboration in healthcare quality and patient safety.

Formative discussions between the study team and knowledge and field experts took place from summer 2009 to winter 2009/2010. These discussions included face-to-face meetings and conference calls. An early draft of the model along with key concepts was shared with members of Patients for Patient Safety Canada (PFPSC) in a presentation made by the study team at the annual general meeting of PFPSC in December 2009. The discussion with this group of patients/families helped the study team assess the current state of the model and concepts which might be important to explore in greater detail as part of the second phase of the study interviews. An early conceptualization of the work was also presented at the Ontario Hospital Association’s “Safety Trailblazers” meeting and the University of Calgary, Department of Psychiatry - Littman Research Day in the spring of 2010.

Ethics approval was received in late 2009 and a total of 14 interviews were conducted in the following year. Six of the participants were patients/family members who had experienced harm and were currently collaborating with various healthcare organizations. Eight of the participants were known healthcare leaders working in this area. The participants were considered to be a convenience sample selected by members of the study team with suggestions provided by CPSI and others based on the participants' experience and relative success working in this area. The interviews were conducted by a research assistant between July and November 2010 in one hour recorded telephone sessions. Written information about the study, the consent form, background about the model, key concepts, and a diagram of the harm to healing journey (Fig. 1) were sent to each of the participants in advance of the interview.

The taped interviews were copied by a transcriptionist and reviewed by the research assistant. No identifying information about the participants (i.e., name) was included in the transcripts. The transcripts were reviewed and themed by the study team using NVivo 8 software [39], applying the principles and methods associated with qualitative analysis. The study team received further assistance in this process from an experienced research academic.

3 - Results

The common and salient themes arising from the interviews were reviewed by the study team in relation to the initial draft model and key concepts. These themes are summarized below.

3.1 - Importance of Assessing Personal Traits

A consensus from the interviews was that some form of assessment of personal assets (personality, skills, experience) is helpful but needs to be balanced with consideration of specific attributes that would be an asset for collaborative work. Such assets would include communication skills (mentioned repeatedly), mediation training, familiarity with healthcare, and an ability to look at an issue from a systems perspective. A mix of these along with a strong desire to help advance the safety of patient care, a constructive attitude, a sense of sincerity and honesty, and a wish to serve the greater good, were all endorsed. There were cautions about 'screening people out' who may not neatly fit into a category and of the need to have "some who may not have gotten over it involved [in this work] because they bring the edge to this work". At the same time it was noted that "people have to feel that they are in a safe environment and this is true for all involved" (patient/family and providers/leaders). It was noted that not all tasks are appropriate for all people but that it is important to find the *right place and a safe place* for this kind of work with those who are committed to improving the healthcare system.

3.2 - Assessing Work Experiences, Values, Beliefs

It was generally believed that experience in large organizations or with groups of people are valuable assets that would be especially applicable to collaborative work in addition to having some understanding, interest or background in safety and quality. Values which were identified as being desirable included respect, honesty, kindness, and a deep belief that something good can come from something bad.

3.3 - Grief and Mourning

It was understood that grief and mourning are processes which require time. The grief and mourning trajectory is unique for each person. It is strongly believed that people need to be far enough along this journey before they are ready to work on collaborative safety improvements without a major risk of being 're-traumatized'. Individuals need to be prepared for the frustrations of this type of work and be able to bring something positive from their own experiences to this work.

3.4 - Motivating Factors

Those interviewed thought that having some understanding of why the person is drawn to this type of work is important to know at the onset of this work. It was thought to be particularly worrisome if the person's agenda was filled with anger and retribution. Positive motivating factors included a desire to see improvements and for change at a larger and systems level. Most who were interviewed thought that some form of assessment of motivation was needed; however, there was one strong voice of dissent. There was uncertainty about the ability to differentiate 'motivation' from 'readiness' and that 'overwhelming anger' might be used as a reflection of not being 'ready' rather than being considered as a factor of 'motivation'. This remains an open question and underlines the tension regarding 'assessment' of people who have been harmed in participating in improvement initiatives.

For most patients or family members, the fundamental motivation is simply to prevent this event from being repeated; preventing harm to others. "It didn't matter what our own personal story was but we just didn't want other families being put in situations of harm." This is reinforced by working with other like-minded people in safety initiatives (including other patients/family members as well as healthcare personnel). The experience of being included in positive change can be healing as well; "I also saw the opportunity for me to achieve some healing through the act of working in this area."

Motivation is also critical for the healthcare leaders and providers. Often, the recognition that patients/families have something unique to offer in the safety arena comes only after some kind of harm event has affected the core of an organization. Some refer to these situations as being a 'burning platform'. It was noted that it may be harder for organizations, leaders and providers when this 'burning platform' is missing. Some have used patient satisfaction as the platform instead of harm but the organization needs to find a strong sense of purpose before beginning this type of collaboration. The drive to do this work can come initially from outside the organization but it absolutely requires support and direction from leadership at the top of the organization; "… recognition from the Board and/or CEO that it is the right thing to do." Some have observed that it has been slower to involve patients and families in safety initiatives when the drive comes from closer to the 'frontlines'.

"I think in order for patients and families and for people working in the healthcare system to stay motivated, there has to be a feeling that progress is being made and it needs to be a visible sort of thing." Sometimes lack of change can provide a kind of drive out of frustration, but most need to see some results from their work. So patients and families continue to work for their goal; "The driving thing is that I would do anything so that another family doesn't have to go through what we went through and this [motivation] hasn't changed."

Ultimately the important changes are ones to the culture of the organization - "…helping staff truly understand what patient/family centred care is. Some of it is that cultural change, really getting beyond to what is the patient experience." There can be tension in organizations where there is pressure to avoid bad press, maintaining damage control and scrutiny, versus being principle-based. Nevertheless, "I don't think we can get to a substantially safer system without using their [patient/family] eyes of experience, their judgment, and comments." "It was helpful to connect with other larger organizations which had made this shift to include the patient and family voice in safety, and discover how well it had gone for them."

3.5 - Readiness to Participate

The organization with its providers and leaders needs to be ready to participate in joint safety initiatives with patients/families. They must be ready to listen, be willing to deal with strong emotions, while at the same time holding firm to the conviction that involving patients/families will bring about positive changes. This requires finding people in the organization who have a natural aptitude in working with patients and families in this domain rather than expecting that all healthcare leaders and providers can do this type of work well. This may require someone to work with the patients and families as their primary work. They need to be prepared to deal with skepticism early on, to building trust as they go. It was noted how some healthcare providers and staff are very uncomfortable with this kind of work and are often concerned and worried about legal action at an individual and organizational level.

Within the organization there needs to be readiness for different opinions; "we can have difficult conversations. If you can't have that in the culture of the organization, you've never going to get anywhere."

Leadership in an organization is key in helping to create the culture and in putting personal examples forward. “It is true that there has to be a lot of reputation management – and this is what the CEO has to consider. You have to have the culture. You have to have the leadership and not only the executive leadership, but others who are able to work with the people and bridge that gap and distance between the upper executive and the group of people involved.” Many at a senior executive level noted that they did not feel fully prepared for this kind of work; “you are never really prepared until you go through it and get some experience with it.”

Some basic organizational issues included having confidentiality agreements with those directly involved and ensuring that the organization and the healthcare providers, and leaders are protected from litigation which might arise from the safety work itself. “The organization prepares by developing key safety policies around a just and trusting culture¸ disclosure, and providing key leaders with training in disclosure. Then, by coming out and saying that we are going to be truthful and transparent and do what’s right for people who have been harmed and preparing staff and leaders to have those difficult discussions with patients and families. These were key pieces at the front end. Then we went on to establish a structure that allows patients and families to provide input – such as a safety council or a quality improvement council.”

Visibility of this work was also noted; it is critical that “the organization has a firm and visible commitment to working with patients and families.”

From the perspective of the patient/family member, readiness is at least in part indicated by the act of putting oneself forward as a volunteer. This self-selection may be the first visible step but “there is no question that there are some people from time to time who may come forward and it is just too early. There is still too much stuff unresolved.” “[I] wasn’t ready until the hospital apologized”. “[I] was doing reading on forgiveness, lots of personal stuff … [until I was] accepting that what happened wasn’t intentional… [and] accepted that they were as harmed as we were and the only way forward is to come together so that this doesn’t happen again.” Just as grief is complex, so is readiness to participate and “that depends on the degree of harm and some of it depends on other personal circumstances – time would be another [factor]”.

Lack of readiness may display itself by showing a great deal of anger or a need to assign individual blame. Some individuals who have been very vocal about their harm experience have joined collaborative safety discussions at a stage when they have been extremely angry. These situations have often been difficult to direct towards constructive actions and relationships. There was agreement that too much anger was an impediment. At the same time it was recognized that some anger is normal and it would be important to look at how the anger might manifest itself in a particular situation (such as a collaborative project) before concluding that it was a substantial problem. The interviewer(s) would benefit from understanding grief, appreciating that coping with loss is not a linear process, and that “there is a difference between eagerness and readiness … eagerness can overwhelm the readiness.”

3.6 - Support / Mentoring

It is important to have a staff member specifically identified to support the patients/family as they work in these safety collaboratives. This may involve having a staff member attend formal council meetings but it may also include more informal and personal support for the patients and families outside of official meetings.

This role needs to be recognized for its worth with endorsement right up to the CEO. It may be helpful to have an identified physician mentor to assist, along with the assigned staff member to assist in support for the patient/family as well. Mentoring and support is also important for the senior leaders, staff, and healthcare providers as they start to work with patients/families in this manner. “Probably the most important thing was that I received mentoring from some people. Without that kind of mentoring, I don’t know that I would have participated to the extent that I did”.

3.7 - Recruiting / Onboarding / Orientation

Recruitment is acknowledged as being a challenge. Some organizations reported using advertizing to help recruit patients/families. Some looked through lists of those involved in harm events. Others contacted their Patient Complaints Office. Some used word of mouth, while others ask for names during patient satisfaction surveys. There was no consensus on a best way to recruit volunteer patient/family advisors. It was noted by some that graduating the involvement of the patient/family in this work over time was ideal. “Our criteria is that you have to be involved in some fashion for a year before you can be on the board” – a sort of ‘getting to know you’ type of recruitment model.

Different organizations have different kinds and varying degrees of onboarding and orientation initiatives. These may range from a simple introductory letter or meeting to a very detailed process which has been developed over a number of years. This may include such things as signing a code of conduct and confidentiality agreement, specific education, police security checks, and registration as a volunteer with the organization. Some organizations have developed workshops to help prepare people for this work including some formal training on patient safety principles with background reading on the organization’s safety policies and practices.

3.8 – Expectations

It is important at the onset of this work that the organization set realistic expectations. It is also important that those involved understand that “how the patient/family is approached and treated from the very beginning sets the stage for this work.” If the approach is positive, supportive and honest, patients/families will be more willing to work with the system to help make important improvements. If the approach is not caring and careful, then these valuable resources may be lost.

3.9 - Getting on with Safety Work

Safety work, in the context of a patient safety committee or council, can be very gratifying, or frustrating, and everything in between. Things which can derail this type of collaboration include involving people who have a lot of anger or frustrations, tackling work or issues that may be too large, poor facilitation, being personally afflicted with repeated harm events, being exposed to others’ recent harm of the same type, significant organizational change, collaborating with people who are ‘stuck’ and continuously reliving their experiences, insufficient direction and support from senior management, or lack of progress on work that has been undertaken.

3.10 - Advice

When given the opportunity to pass along advice to anyone starting up a patient/family safety council or collaborative engagement work, the following suggestions were offered:

- Commitment from senior leadership (even the organization’s board of directors) for this work
- People in dedicated positions, with dedicated time to work with patients/families so that this isn’t being done off the sides of people’s desks
- Transparency, honesty and trust need to be actively demonstrated within the organization
- An initial or introductory meeting where the patients/families can share their experiences and where healthcare leaders, staff and providers have the opportunity to listen to what has happened from the patient/family perspective
- Recognition of the patient/family’s ability to hear and see things that aren’t working well
- Appreciation that there are some things that we can only learn directly from patients/family

4 – Final Model

The model begins with people in their normal lives functioning in their usual way (as noted on the sidebars as positive psychological wellbeing). In depicting the fact that life has its usual ups and downs, this part of the pathway is not straight. The study team recognizes that the journey may apply to both the patient and their family.

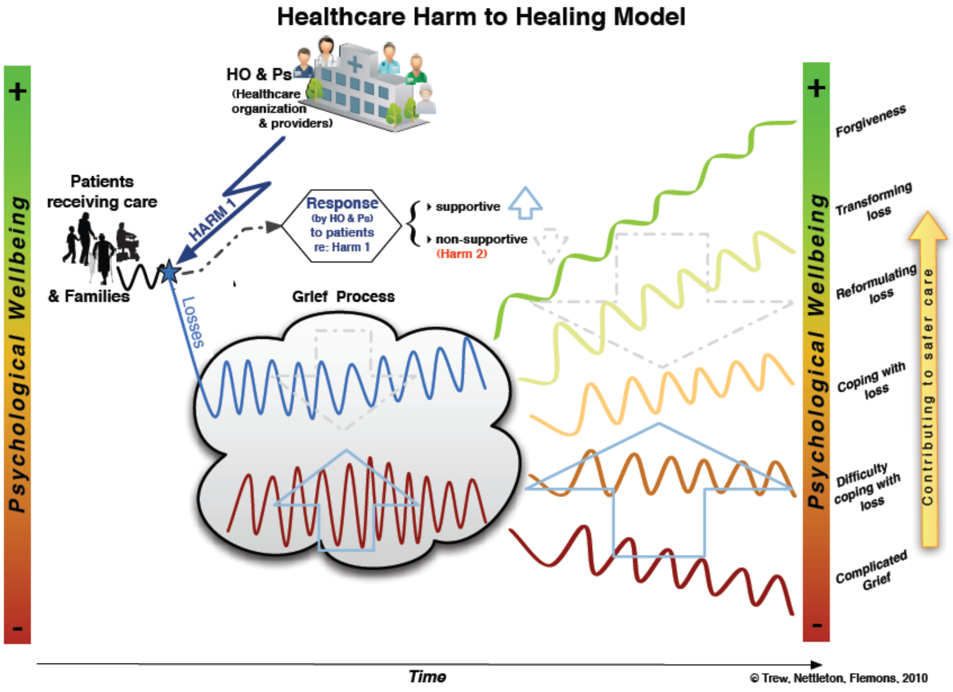
The star icon depicts the harm event – *Harm 1*. This is a distressing event and psychological wellbeing drops precipitously. It may also be associated with other losses that are associated with the harm (i.e., loss of job and income, loss of mobility, etc.). From this point on, the healthcare organization and the providers have opportunities to respond. If these responses are viewed as *supportive* from the patient/family perspective (e.g., with appropriate apology and disclosure), then the experience may be helpful to the patient/family and assist in dealing with the losses. If the healthcare organization and its leaders, staff and providers do not listen, apologize and appropriately disclose the harm, the experience is more likely to be *non-supportive*. This may complicate the grieving process leaving the patient/family with unresolved questions and emotions. It may also contribute to problems with anger and trust.

The *grief process* is pictured as a cloud with two wavy lines. The intent is to portray grief as a process that does not have a clear or simple endpoint. Grief as described in the 'dual process model' resonated with the study team and has been incorporated into this framework [56]. The duel process model describes two groups of activities; one which attends directly to the loss, and the other which is directed at getting on with life. This may be apparent in persons who have been harmed in healthcare, and who may be able to engage in collaborative work sometimes, while on other occasions want to distance themselves from this work. Meanwhile, the response from the healthcare organization may continue to be *supportive* and helpful or *non-supportive* and possibly even harmful – *Harm 2*.

The side of the diagram to the right suggests that not all people recover from harm to their previous level or state of psychological (not to mention physical) functioning. This will depend on many factors including their own inherent resilience, access to other supports, and any further interactions with leaders, staff and providers in the healthcare organization. The spectrum of functioning at a later time (measured in months to years and dependent upon the seriousness of the harm) is considerably variable, from situations of complicated grief (see Section 1.6a above) that might be prolonged, to those where there is faster and more complete psychological recovery.

It is helpful to use this model when discussing recovery with a patient/family member as it helps to explain and identify grief and recovery as a process which unfolds over time. It also helps outline the impact that leaders, staff and healthcare providers can have in helping or hindering recovery, healing and possibly even forgiveness. It is not expected that recovery from harm needs to be "finished" or "fully resolved" in order for someone to be engaged in collaborative safety work, but it does imply that if involvement occurs too early, there may be too many conflicting emotions to be involved in this work at a productive level.

Fig. 2



5 – Good Practice

In reviewing the experiences of the patients/families and experts who were interviewed as part of this study along with the knowledge and experiences of members of the study team, a number of themes emerge. These are described as “good practices” for this type of collaborative work and are outlined below.

Invitation

The initial contact between a patient/family member and the organization, inviting them to be part of this work should be at a *personal level* (i.e. made directly person-to-person). This can be augmented by further information in writing on a website, poster or brochure.

Background Information & Expectations

It is helpful to have background information for prospective volunteers available at the time when they are considering this work. This information should outline the work at hand, expectations of volunteer time and the period of commitment , examples of previous collaborative work, and realistic suggestions about what this is like for those who have been involved (i.e., patients/families, providers, staff and leaders).

Conversation

A patient/family member contemplating this type of work should be able to speak to someone who is well-acquainted with this type of work prior to making any commitment. The conversation should address the person’s experience of harm, the experience they have had with the healthcare organization (i.e., whether there was second harm) and if there is any known need for further information or disclosure. This can be especially important if the harm took place in the organization that is wishing to collaborate with the patient/family. It is useful to have the interested patient/family identify what they see as their strengths, and what they may see as possible challenges. The goal of this type of discussion is not to eliminate possible collaborators but rather to help assess the ‘fit’ between the people who will work together and the *safety* *task, project* or *initiative*. It might be useful to see this as a metaphoric ‘date’, where both parties check out the suitability of the other in pursuit of a ‘good fit’ partnership.

Graduated involvement

Wherever possible, it makes sense to involve those who are new to the organization or to this type of work in a graduated fashion. This implies having different types of activities, from relatively straight-forward, less time consuming *tasks,* to longer-term *projects* with greater time commitments, to *initiatives* that may be more complex, involved, and on-going such as participating in a safety council.

Orientation

Orientation to collaborative patient/family safety engagement is an important step in ensuring success. It generally begins with an introduction to key people who will be part of the engagement *tasks*, *projects* or *initiatives*. It involves learning more about the understanding and expectations of the roles of patients/family members with leaders, staff, and healthcare providers. There is a greater likelihood of success where there is mutual understanding of previous experiences, clarity of roles and expectations, and access to general background information about patient safety.

Support

Due to the intensity of the experience of harm in healthcare and even if *forgiveness* occurs, most people will not forget these events and could be emotionally impacted and triggered by hearing of other similar experiences. As such, there needs to be some degree of ongoing *support* available to the patients/families and staff, healthcare providers and leaders involved in this work. This is especially the case for those where the harm has been particularly severe. A careful balance must be struck to avoid situations where the collaboration becomes the major emotional support for the individual. ‘Rules of conduct’ are helpful which enable people to ‘step aside’ when they need to take a break from this work. It is particularly helpful to have a person from the healthcare organization who is identified for both administrative and emotional support. It is important that the norms of the group are known and discussed by everyone early in the engagement process.

For the Organization

High level support

It may not be possible to effectively and respectfully engage people who have been harmed in safety work without the support of the board of directors/senior leaders/administration in the healthcare organization. Without senior level support, there is considerable risk of further loss of trust among those involved which may result in feelings of *betrayal* and further harm for all involved (see also points below regarding Disclosure, Resourcing and Expectations which will involve decisions from senior leaders).

Disclosure

In order to be involved in this kind of work, most patients/families who have experienced harm will require disclosure of the facts and a timely and appropriate apology prior to being involved in this type of collaboration. Those with experience in this area have noticed that if these steps do not take place, an antagonistic relationship is often created. The patient/family member finds it extremely difficult to look at larger systems issues when the process for resolving their own situation has not gone well. In these cases, it is more important to assist at the individual level before attempting work at a larger systems level.

Resourcing

Involving patients/families who have been harmed in a healthcare setting requires designated *support* for both *administrative* and *emotional purposes*. This includes everything from coordination of meetings, practical assistance with way-finding, ensuring reimbursements for out-of-pocket expenses, to aid in interpretation of documents and use of new technology. This will be more than repaid for in good will, transparency, and the insight that committed patients/families, healthcare leaders, staff and providers will bring to this work. The work requires an investment of time, attention, and resources.

Expectations

It is important to openly discuss and identify what the expectations of this type of engagement are at the outset of this work with the patient/family volunteers. This can take the form of outlining both the positive expectations and initial fears and concerns. To highlight the point above concerning emotional impact of being involved in this work, it is not realistic to expect that engagement with patients/families who have experienced harm can occur without reasonable *emotional support*, especially with longer projects or initiatives. At the outset, those involved need to know that they or others could become emotional and deeply affected by this work. They should know how they can access resources to help manage their emotions and the impact of the work in a reasonable and respectful manner if necessary.

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