



National Hospice and Palliative Care Organization
Palliative Care Resource Series

**CARING FOR HOLOCAUST SURVIVORS
AND SURVIVORS OF OTHER TRAUMATIC
EVENTS AT THE END OF LIFE**

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INTRODUCTION

When providing services to Holocaust Survivors, it is important that we are mindful of our words and actions, especially since we will be the last generation of caregivers and clinicians who have the honor of delivering compassionate health services to this special population. Caring for Holocaust Survivors at the end-of-life is particularly rewarding when care leads to a peaceful passage at the end of the natural life span, an experience denied those who were brutally murdered during the Nazi regime. The focus of this paper will be the provision of Palliative Care to Holocaust Survivors, but there are similarities when providing care to survivors of other traumatic events, such as Veterans.

THE NEED

Definition of Holocaust Survivors

Holocaust Survivors are persons who lived in one of the countries occupied by, or under the influence of, the Nazi regime for any length of time between 1933 and 1945. Included in this group are those who were forced to flee their place of residence because of persecution by the Nazis. Survivors may have experienced uprooting, deportation, forced labor and/or extermination camps. They also lived as refugees under false identities, in hiding or perpetually on the run. Depending upon where they lived, individual survivors may have suffered under Nazi persecution for up to six years. All Survivors lost family members, a good portion survived along with a small number of relatives, while others were sole survivors of large extended families.

Definition of the Holocaust

The Holocaust was a state-organized, systematic attempt to annihilate all European Jewish communities and physically exterminate all individuals of Jewish descent. The Nazis referred to this plan as the "Final Solution to the Jewish Question."

The magnitude of suffering imposed on millions of innocent people remains unimaginable, yet it is fully documented and impossible to deny. Prior to 1933, there were nine million Jews living in Europe. The term "Holocaust" refers to the systematic extermination of 6 million Jews between 1933 and 1945.

While the "Final Solution" was an answer to the "Jewish Question", it is important to note that not only Jews were targeted by the Nazi regime. People of color, gypsies, homosexuals, Catholics, Jehovah's Witnesses, the physically and/or mentally disabled, the elderly and the very young were all considered expendable and were targeted for torture, experimentation, labor or death. Hitler's quest was to cleanse Europe and create a master Aryan race, devoid of inferior non-Germanic populations.

Most Survivors started new lives with new families but endured the challenges of being strangers in strange lands and were burdened with eternal memories of horrors that could never be erased. Holocaust Survivors have always been seen as individuals who have shown the capacity for strength and resilience. Indeed, many demonstrated a remarkable capacity to cope under extreme circumstances.

Grieving and mourning were difficult for many Survivors. For the knowing eye, there are tell-tale signs of the horrible pain Survivors hold within them. Most require no questioning but do require understanding, because as Survivors age and face illness, their repressed long-term traumas may resurface. Survivors who buried and tucked away the horrors they lived through, find themselves in situations where they need to talk about their past¹. Situations that trigger the re-experiencing of trauma create difficult to address challenges for the caregiving team.

IMPORTANCE FOR PALLIATIVE CARE PROFESSIONALS TO LEARN ABOUT THIS POPULATION

The Holocaust, or *Shoah*, ended in 1945, and today, in 2016, we are seventy-one years post World War II. Considering that the average age of Holocaust Survivors is 79 years, with more than a quarter over 85 and the oldest over 100, caregiving teams are often not familiar with or knowledgeable about the experiences of these Survivors and how their traumas manifest as they become seriously ill.

This population has unique needs which are based on a complex and pervasive history of suffering and trauma and which are expressed through symptoms of PTSD that are often exacerbated at end-of-life. Hospice and palliative care professionals must gain a deeper understanding of related issues and behaviors specific to these individuals, in order to avoid misunderstanding or misinterpretation.

HOLOCAUST SURVIVOR FACTS AND FIGURES²

- In 2010, an estimated 127,300 Nazi victims were residing in the US; approximately 75% were at least 75 years of age.
- In 2015, the total number of living Survivors was estimated at 98,400
- In 2020, it will be 67,100 and all Survivors will be at least 75 years old; over half (57%) will be at least 85 years old.
- In 2025, there will be 36,800 Survivors and by 2030, the number of Survivors still living is estimated at 15,800.

The highest proportion of Holocaust Survivors resides in New York City, with the largest concentration found in Brooklyn. Selfhelp's³ revised demographic report published in 2009, projects that in 2015 there were 56,748 Survivors in the NYC Metropolitan area, by 2020 there will be 38,111 (all older than 75) and by 2025 there will be approximately 23,400 Holocaust Survivors living in the New York City Metropolitan area.

¹Wardi, Dina MSW. Bonding and Separateness, Two Major Factors in the Relations Between Holocaust Survivors and Their Children. 1994 p. 122-123

²Jewish Survivors of the Holocaust Residing in the US. Estimates and Projections: 2010-2030; Miller, Ron Ph.D., Berman Institute-North American Jewish Data Bank; Beck, Pearl Ph.D., Ukeles Associates, Inc.; Torr, Berna Ph.D., California State University-Fullerton, 2009

³Selfhelp Community Services, Inc., Second Edition with Newly Released Demographic Information report "Holocaust Survivors in New York Today Through 2025. (Published in 2009)

What the national and NYC statistics indicate and stress is that the last generation of Survivors will have complex needs. While the number of living Survivors will decline rapidly, their need for services will continue to grow as Survivors age, increase in frailty and confront advanced and serious illness.

MJHS HOSPICE AND PALLIATIVE CARE – TWO-YEAR HOLOCAUST SURVIVOR GRANT

MJHS Hospice and Palliative Care is located in New York City, in the heart of the largest Holocaust Survivor population in the United States. We are seeing an increase in the number of Survivors served. In 2015, we cared for 180 Survivors and in the first half of 2016, we cared for over 100, with an expected growth of 15-20% by year's end.

MJHS Hospice and Palliative Care was awarded a two-year Holocaust Survivor grant aimed at gaining a better understanding of the attitudes of Survivors about advance care planning and access to end-of-life care. The goal was and remains to increase access and identify best practice when caring for Survivors and their families.

MJHS accomplished its goal in several ways:

1. A Holocaust Survivor Survey was conducted.
2. Full-day museum-based educational programs were developed and implemented. Each day included a Holocaust exhibit tour, a presentation by a Holocaust Survivor, a didactic presentation about the impact of trauma and aging on Holocaust Survivors, Q/A and debriefing.
3. MJHS incorporated Holocaust Survivor sensitivity education into its onboarding and orientation process for new employees.
4. Training and education for Home Health Aide agencies used preferentially for Holocaust Survivors was initiated.
5. A guidebook for clinicians who care for Holocaust Survivors was developed (available electronically hospicenyc.org/holocaust-booklet).

1. Holocaust Survivor Survey

The framework of the survey consisted of four sample populations, each with a minimum of fifty participants. The participants were Holocaust Survivors, Non-Holocaust Survivors, Second Generation Holocaust Survivors and Second Generation Non-Holocaust Survivors. There were no parent/child relationships between first and second-generation participants.

The impetus behind the survey was our experience with Survivors as clients who could be challenging to serve.

Survivors were:

- Often suspicious of strangers
- Non-compliant with treatment plans
- Extremely anxious
- Difficult and demanding
- Exhibited a lack of intergenerational communication around healthcare decision making, particularly when confronting advanced or serious illness.
- Frustrating for professionals who cared for Holocaust Survivors and Second Generation Holocaust Survivors. Uninformed about hospice services, and did not care to know about them.
- Resistant to hospice, which resulted in patients coming onto hospice care very late and in their final stage of terminal disease.

2. Key Survey Findings

- 100% of Holocaust Survivors reported fear of becoming a burden to their adult children/family. Only 2% of Non-Holocaust Survivors reported a similar fear.
- 0% of Holocaust Survivors reported a fear of dying. 41% of respondents in the Non-Holocaust Survivor group reported a fear of dying.
- 26% of Second Generation Survivors reported that their Survivor parents discussed their healthcare wishes with them, compared to 85% of adult children of Non-Survivors.
- 8% of Second Generation Survivors initiated conversations with their parents, while 77% of adult children of Non-Survivors initiated healthcare conversations.
- 78% of Holocaust Survivors feared loss of independence compared with 15% of Non-Holocaust Survivors.
- 75% of Holocaust Survivors relied on their children to make healthcare decisions for them while 81% of Non-Survivors relied on doctors to make healthcare decisions.

3. Understanding the Findings

The data tell an interesting story that highlights the impact of trauma-related issues. Holocaust Survivors, who have already survived unnatural death, are unafraid of dying after a full life and rely heavily on their adult children and family to take care of them and make decisions for them. Yet, the majority of Survivors do not have advance directives in place. They avoid discussions about dying and/or healthcare wishes with their children, for fear of becoming a burden to them. At the same time, the children feel obligated to care for and protect their parents, but are unable to initiate conversations for fear of breaking the pattern of silence around these sensitive and painful topics.

Both parent and child are trapped in a conspiracy of silence out of love and concern for the other, creating a vacuum in which missing information could ease the burden for both during an emotionally charged end-of-life journey. This reality often translates into challenging dynamics between the parent and child, creating frustration for them and difficulties for the clinical team. The parent trusts the child to make decisions but does not help and empower the child with vital information to illuminate goals of care, ultimately placing the greatest burden imaginable on the child. The child vigilantly protects the parent with the aim of keeping him/her alive.⁴

⁴Metzger Brown, Eva Ph.D., *The Transmission of Trauma Through Caretaking Patterns of Behavior in Holocaust Families: Re-Enactments in a Facilitated Long-Term Second-Generation Group*, 1998 p. 268-285.

These complex issues may be further exacerbated by Survivor patient comorbidities that include depression alongside PTSD, which if not assessed can lead to misunderstanding on the part of the caregiving team. Additionally, children of Survivors, may manifest transmission of trauma through hypervigilant, micro-managerial and demanding behaviors that complicate care planning and lead to alienation by the caregiving team.

Some ways to overcome these challenges:

- Provide education for healthcare professionals and caregivers about the Holocaust and the impact of PTSD. We learned that talking about healthcare wishes was not difficult for Holocaust Survivors – they just did not want to discuss it with their children.
- Engage skilled third party facilitators who can initiate difficult conversations between parent and child. Social workers are excellent resources to carry these conversations to conclusion, which is often an iterative process.
- Explain that the added benefit to facilitated conversations about healthcare decisions and advance care planning is that the adult child can feel comforted by being able to carry out the parent’s wishes, without guilt.

Effects of Traumatization

The effects of traumatization include PTSD, depression, panic disorder, generalized anxiety disorder and substance abuse – all of which are common comorbidities of PTSD. First documented as a psychiatric diagnosis in 1980, PTSD was defined by the DSM-IV (APA, 1994) as an anxiety disorder that arises from exposure to a traumatic event that involves actual or threatened death or serious injury.

When applied to the definition of the Holocaust as the state-organized, systematic attempt to annihilate all European Jewish communities and physically exterminate all individuals of Jewish descent, there is a clear correlation. Furthermore, within the Holocaust Survivor community “survivor guilt” and distrust of authority are also considered comorbidities.

Studies suggest that there is great variability in individual responses to traumatic stress and that not all people develop PTSD⁵⁶. There is a strong association between trauma exposure and the physical and psychiatric symptoms observed in victimized populations.

Survivors of the Holocaust have always been viewed by others as strong and resourceful individuals with the capacity to move beyond the tragedies of their past. Moving forward was accomplished, to some degree, through the “conspiracy of silence” that kept the darkness of the past tucked away. Survivors did not simply survive; they demonstrated remarkable resilience as they rose from the ashes of destruction to build new lives. Most married, had children, immigrated to other countries and succeeded in business.

⁵Ibid
⁶Opcit

In a study of 23 Holocaust Survivors (Yehuda et al.), it was found that Survivors with PTSD had a greater degree of depression and a wider array of depressive symptoms than Holocaust Survivors without PTSD or in demographically matched control subjects.⁷

- Clinical observations show that trauma can be stirred up by normal aging processes, like increasing illness, frailty, dependency, isolation, loss of significant others and impending personal death.⁸
- The work of Trappler, Cohen and Tulloo which explores the impact of early lifetime trauma on the later Life of Holocaust Survivors, found that prevalence of depression and PTSD symptoms is very high in Survivors.
 - ◆ Depressed Survivors also have significantly worse psychosocial functioning than depressed non-Survivors do.
 - ◆ Depressed Survivors have more PTSD symptoms than non-depressed Survivors do.

SYMPTOMS TYPICAL OF PTSD

Re-experiencing

Re-experiencing of trauma expresses itself as repetitive disturbing memories, nightmares, hallucinations and flashbacks that intrude unbidden in the Survivor.

- The Re-experiencing of trauma can result from sirens, doctors/lab coats, identification tags/ labels, removal of clothing or disrobing, pre-surgical markings, harsh smells of urine/feces, holding areas, medical procedures, family members leaving, staff changes, group organizing.
- Re-experiencing manifests through unbidden memories that suddenly intrude on a person's day or in their sleep⁹.
- Examples of triggers leading to re-experiencing may include being strapped on a gurney and not being able to move – reminiscent of being trapped in cattle cars or in barracks.
- Surgical markings may trigger memories of dehumanizing experiences, such as tattoos branded on forearms of concentration camp prisoners and being reduced to mere numbers or objects.
- Injections or medical procedures can evoke memories of inhumane and forced medical experiments on Nazi victims.
- Acts of dehumanization such as disrobing, forced line-ups, being stripped of personal belongings can all resurface in hospitals and other institutional or caregiving settings.

Avoidance

Avoidance consists of attempts to avoid reminders of the trauma associated with people, places and things.

- Avoidance manifests as lack of participation in family events or isolating oneself from social functions or people and may cause frustration and resentment by family members and caregivers.
- Typical presentation in clinical settings may involve denial of illness and symptoms or refusal to see a physician, insisting there is "nothing wrong" as well as non-adherence to treatment plans.

⁷Yehuda R, Kahana B, Soutwick SM, et al: Depressive features in Holocaust survivors with post-traumatic stress disorder. J Trauma Stress 1994; 7:4699-4704

⁸Brandler S: Understanding aged Holocaust survivors. Families in Society 2000; 81:66-75

⁹Metzger Brown, Eva. The Transmission of Trauma Through Caretaking Patterns of Behavior in Holocaust Families; Re-Enactments in a Facilitated Long Term Second Generation Group. Smith College Studies in Social Work, 1998).

Numbing

Numbing refers to the suppression of trauma-related memories and emotions, sometimes leading to amnesia regarding aspects of the trauma, or a sense of being “emotionally numb.”

- Numbing is often misunderstood as detachment and lack of engagement that results from suppression of trauma-related memories that are too difficult to bear, rendering a person numb.
- Typical issues include emotional distancing and the inability to show emotions rendering a flat affect.

Hyperarousal

Hyperarousal is commonly evidenced by hypervigilance, irritability, exaggerated startle response and sleep disturbance, explosive reactions and intrusive or micro-managerial behavior patterns.¹⁰

- Hyperarousal manifests as rigidity related to expectations, time-sensitivity or urgency, hoarding or hiding food, worry/anxiety and separation from family.
- Hypervigilance is often a source of friction between Holocaust Survivors and professional caregivers or adult children/spouses.
- Removal of food can trigger memories of starvation.
- Sitting idly without performing work-related tasks can trigger reactions because of punishment and beatings for perceived inefficiency in labor and concentration camps.
- Arriving late/leaving early, worry about time related appointments and matters, distrust of strangers and suspicions of motives and behaviors can cause fearful reactions.
- Disclosure of financial information can be a source of suspicion, as Survivors were robbed of all their possessions.
- Medical consultations can be a source of distrust and suspicion due to betrayal by clinical personnel during the war.

REACTIONS OF HEALTH CARE PROVIDERS TO DIFFICULT BEHAVIORS

It is commonly believed that physicians and other healthcare professionals go into medicine to heal and to help. Physicians take an oath to do no harm and to use their knowledge and skills for the greater good. Yet, history is replete with undeniable evidence of physicians participating in inhumane behaviors¹¹ that breach all ethical standards and that would be considered criminal today.

Doctors played a key role in the killing machine known as Auschwitz. How is it possible and what rationalization can be applied to the implementation of “negative eugenics”? How are we to comprehend genocidal programs, such as mass sterilization (1933) and the euthanasia program (1939-1941) which were based on Nazi racism and informed by principles of biological determinism?¹² The barbarism and inhuman experiments performed by “Dr.” Mengele and other clinicians during the Holocaust present a grotesque image that elicits reactions of disgust and disbelief from healthcare professionals today.

¹⁰Felsen, Irit, Ph.D. Trauma, Aging and Implications for Treatment: When Holocaust Survivors Need Our Help Most. May 2012

¹¹Tuskegee Syphilis experiment in Alabama carried out on rural African American men for 40 years (1932-1972). Informed consent for Human Subjects in clinical studies was one of the changes implemented after this horrible event in U.S.

¹²Lifton, Robert Jay. The Nazi Doctors: Medical Killing and the Psychology of Genocide. Basic Books. P. 561

Despite first person accounts and historical documentation attesting to an undeniable truth, healthcare professionals may consciously or unconsciously deny the possibility of their involvement in these types of practices today.¹³

- Dr. Irit Felsen¹⁴ analyzes the defense mechanisms employed by medical professionals to distance and protect themselves from the undeniable role physicians and nurses played during the years of the Holocaust. She describes “superiority” as the belief that we have nothing in common with perpetrators of such evil. Yet, the Nazi physicians were highly educated, cultured and part of society’s elite.
- Felsen also cites “irrelevance,” suggesting that clinicians may rationalize that such atrocities could not be committed today and are, therefore, irrelevant. (Yet, we have examples throughout history including Tuskegee, Cambodia, Bosnia, Syria, etc.) Finally, Felsen points out “judging,” which can occur when a clinician, consciously or unconsciously, displaces blame on victims as a method of reconciling a disturbing reality, which in turn, can lead the clinician to reject or avoid Survivor patients.

Dr. Robert Jay Lifton,¹⁵ a psycho-historian, has written extensively about the concept of “doubling” as an enabling factor in healers becoming killers throughout documented genocidal experiences.

- Lifton describes “doubling” as the process that allowed doctors to commit diabolical acts in concentration camps without emotional distress while continuing to see themselves as humane and civilized physicians.
- He describes “socialization to evil” developed through joining the Nazi party, the military system, and being sent to Auschwitz where physicians were socialized into a killing process.
- Physicians adapted to what Lifton calls the “Auschwitz Self,” allowing them to participate in horrific acts of evil, like routine selections, human medical experiments and cold murder. These same physicians, however, would go home to their families for weekends and would be ordinary fathers and husbands who functioned in ordinary ways, in their humane non-Auschwitz selves.
- Further, Lifton emphasizes that each of these selves functioned as though it were a separate autonomous self, and therefore he called this “doubling.” The ultimate take-away for healthcare professionals today is that we all may be susceptible to doubling, particularly in the medical field. Maybe even more so in the end-of-life space because of repeated encounters with death and suffering. Thus, medical professionals must guard against desensitization to the patient’s pain and humanity.

RECOMMENDATIONS FOR HEALTHCARE PROFESSIONALS CARING FOR HOLOCAUST SURVIVORS AND OTHER VICTIMS OF TRAUMA

- Be cognizant of your own history or experience of personal trauma, so you can remain sensitive to the trauma of others.
- Maintain professional boundaries by being value-neutral so you can practice patient-centered care without personal bias.

¹³Felsen, Irit Ph.D., *Trauma, Aging and Implications for Treatment: When Holocaust Survivors Need Our Help Most* (New York: 2011)

¹⁴Ibid

¹⁵opcit

- Be tolerant of others and see each patient as an individual and whole human being.
- Resist desensitization to the pain and suffering of others. Be compassionate and empathic to patients and families.
- When learning of a patient's traumatic experience, listen attentively and be cognizant of your own verbal and non-verbal messaging.
- When working with Holocaust Survivors, speak calmly and patiently and explain what you are doing, and why.
- When speaking with Holocaust Survivors and their adult children, ensure that what you say is understood accurately.
- When interviewing and examining Survivors, assess for trauma and listen without interruption and with patience. Being assessed for trauma can trigger a re-experience of the actual trauma.
- When physically handling patients be gentle and avoid harsh and forceful movements.
- If pain or discomfort is expressed, validate this experience, and assure the patients that you are not indifferent to their suffering.

CONCLUSION

Over years of practice, you will encounter many people who are different from you and who may have experienced unthinkable traumas that have scarred them for life. Learn to resist tendencies that can lead even you, the well-intentioned professional, to behave inhumanely. Left unchecked, all people are capable of committing atrocities. We are duty-bound to treat our patients as no less human than ourselves.

ADDITIONAL RESOURCES

1. Guidebook for Clinicians developed by MJHS Hospice and Palliative Care can be accessed at hospicenyc.org/holocaust-booklet
2. Potential triggers for Holocaust Survivors can be accessed at www.baycrest.org/HolocaustSurvivors/triggers.pdf