

CARING FOR
H O L O C A U S T
S U R V I V O R S

WITH SENSITIVITY
AT END OF LIFE

A Guidebook for Clinicians

Dear Colleagues,

As clinicians and professional caregivers whose mission it is to manage pain and suffering, we are bound by an oath to “do no harm” and to provide culturally sensitive care. When providing services to Holocaust Survivors and war victims, it is important that we are mindful of our words and actions—particularly because we may be the last generation of caregivers and clinicians who have the honor, as well as the moral obligation, of delivering compassionate health services to Survivors.

As one of the largest hospice programs under Jewish auspices in the region, MJHS understands that members of the Jewish community have different levels of observance, and so we tailor our hospice program to meet the individual spiritual and religious practices of each patient. For those who wish to participate, we offer the *Halachic* Pathway—which is funded by MJHS Foundation and ensures that end-of-life decisions are made in concert with a patient’s rabbinic advisor and adhere to Jewish law and traditions. Our sensitive care to Holocaust Survivors and their families takes into consideration the unique physical, emotional, social and psychological pain and discomfort they experience when facing the end of life. This is one of the many reasons why we seek to share our insights and experiences.

This guidebook is for clinicians who have never, or rarely, worked with Holocaust Survivors. It is meant to help users gain a deeper understanding of end-of-life issues that may manifest in the Holocaust Survivor patient, especially ones that can be easily misunderstood or misinterpreted.

We are confident that this guidebook will:

- Be an educational tool and resource for professional caregivers serving Holocaust Survivors and their children, the Second Generation
- Educate clinicians about how post-traumatic stress disorder (PTSD) manifests itself at the end of life in Holocaust Survivors
- Raise self-awareness of their own comfort levels and reactions in clinicians and caregivers when working with Holocaust Survivors

The material in this guidebook has been compiled from multiple sources. It is, however, largely based on a keynote lecture by Irit Felsen, Ph.D., Clinical Psychologist and Trauma Specialist and an Adjunct Professor, Yeshiva University Ferkauf School of Graduate Psychology. Her lecture was part of an MJHS-sponsored educational program for clinicians and professional caregivers entitled “Their Last Days: Aging Holocaust Survivors Facing the End of Life,” which was delivered at the Museum of Jewish Heritage in New York City. In addition, her guidance, feedback and support helped us create this educational tool with practical application.

Baycrest, a Toronto-based geriatric care health system, renowned for its expertise in caring for Holocaust Survivors, is also a key resource. The Canadian organization’s practical manual called *Caring for Aging Survivors of the Holocaust* is a valuable reference book for all caregivers working with Holocaust Survivors.

MJHS is committed to delivering compassionate expert care while offering peace of mind and providing comfort. We were founded in 1907 by the Four Brooklyn Ladies. Generous charitable support from their community enabled them to establish the Brooklyn Ladies Hebrew Home for the Aged. Rooted in the core Jewish values of compassion, dignity and respect, the home offered frail, elderly members of the community quality health care and a safe place to live in their time of greatest need.

Today, those same core values continue to guide us. From the small building among the tenements, we’ve become one of the most expansive health systems in the region.

We offer patients and their families an opportunity to live life to the fullest. As a charitable not-for-profit, our focus is on easing suffering, upholding dignity, affirming values and improving quality of life for patients at home or in the hospital, assisted living communities, nursing homes or one of the exceptional MJHS Hospice Residences in Greater New York.

From the first to last pages of this guidebook, we hope you remain informed and inspired.

Sincerely,

MJHS Hospice Caregivers



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Section

1

Learning Objectives and Context

In the course of this guidebook you will learn:

- Ways to provide care to Holocaust survivors.
- How post-traumatic stress disorder can manifest itself in routine care.
- Ways to recognize and address relationships in the context of First and Second Generation family members.

Historical Overview of the Holocaust

The Holocaust, or *Shoah* in Hebrew, refers to the systematic, deliberate and carefully planned attempt to annihilate all European Jewish communities and to exterminate all individuals of Jewish ethnic ancestry. In early 1933, the Nazi party came to power in Germany, and under Adolph Hitler's rule it implemented the persecution and segregation of the Jews in minutely organized stages. In addition to Jews, other groups were persecuted and murdered, including the Roma, homosexuals, Jehovah's Witnesses, the mentally and physically disabled and anyone who was not of the racially pure Aryan stock. State-sponsored racism introduced and supported anti-Jewish legislation, economic boycotts and confiscations as well as isolation of the Jews from all classes of the general population (e.g. schools/universities, hospitals, etc.). The plan came to be known as the Nazis' "Final Solution to the Jewish Question."



On September 1, 1939, the Germans invaded Poland. This single event is most often cited as the start of World War II. During the next several years, much of continental Europe was conquered, subdued and devastated by Germany. Anti-Jewish proclamations escalated rapidly and led to the imprisonment of Jews and, eventually, to the murder of most European Jewry. First the Nazis established sealed ghettos to which they deported Jews from Poland, Western Europe and the Balkan nations in order to segregate and confine them. These ghettos were extremely overcrowded and unsanitary, and the Jews suffered from starvation, contagious diseases and overall inhumane living conditions.



In 1942, the Nazi authorities throughout Europe began the systematic deportation of Jews to concentration, extermination and/or forced labor camps established in Nazi-occupied Europe. Jews, already segregated in established ghettos or in small towns and villages, were rounded up and transported in overcrowded cattle cars to different extermination camps and mass-killing centers to be gassed to death. Only those who were deemed fit for forced labor—the young and healthy—were not immediately murdered upon arrival. Additionally, in many of the concentration camps, Nazi physicians performed forced medical experiments on Jewish inmates without the use of sterile equipment or anesthesia. Typically, these experiments resulted in death, disfigurement and permanent disabilities, including sterility.

Section

1

Definitions and Terminology

Who is considered a “Survivor?”¹

Survivors of the Holocaust are defined as persons who lived in one of the countries that was 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, therefore, may have experienced uprooting, deportation, labor and/or extermination camps. They may have lived under false identities, in hiding or been perpetually on the run. Depending on where they lived, individual survivors may have suffered under Nazi persecution for up to six years.

Key Words²

Shoah:	Hebrew word for the Nazi Holocaust
Holocaust:	The persecution and murder of European Jewry during World War II
Nazi:	The ruling party of Germany during World War II and also a person who was a member of the party
Hitler:	Leader of the Nazi party who initiated World War II and the Holocaust. He ordered and supervised the murder of European Jewry
Final Solution:	The official Nazi term for the extermination of all European Jewry
Ghetto:	A sealed and fenced/walled area of a city to which Jews were confined under overcrowded and unsanitary conditions
Camps:	All the locked and guarded areas where Jews were imprisoned <ul style="list-style-type: none"> • Labor Camps: Jews were barely kept alive and used for slave labor • Concentration camps: Holding areas where people starved to death, were used in inhumane medical experiments or were eventually killed • Death or extermination camps: Set up for the specific purpose of systematically exterminating all inmates. (Near the end of the war, most camps became death camps.)
Lager:	German word for “camp.” Often also referred to as the sleeping barracks in the concentration, slave labor and death camps
Partisans:	Underground resistance fighters, including many Jewish men and women
FSU:	Former Soviet Union émigrés are also defined as Holocaust survivors and entitled to compensation as of January 2012

¹ Caring for Aging Survivors of the Holocaust (Toronto: Baycrest.org)

² Ibid, P.63

Section

2

Helpful Strategies for Working with Holocaust Survivors

Ways to identify a Holocaust survivor

Asking simple questions can help identify a Holocaust survivor without directly asking. Clues include place of birth, date of birth, date of immigration to the United States, religion and languages spoken. Indications that a person is a Holocaust survivor include heavily accented English, Russian or European languages spoken, lack of family members of same generational age and a number tattoo on the arm.

How to gather crucial information

It is often difficult to obtain information from Holocaust survivors about their past. They may not wish to revisit and disclose details about their past experiences. Once a patient is identified as a Holocaust survivor, it is imperative that health care providers explain how the patient's personal information will be used.



For example: When conducting a clinical assessment, be specific about required information and how it relates to appropriate care. This builds trust and assuages suspicion about the clinician's motives.

Be sensitive to the fact that during the war, doctors and nurses conducted human medical experiments and meted out inhumane treatments to “undesirables.” If you are a health care provider, you must be cognizant of the potential effects of certain behaviors and treatments.

For example: If a clinician asks for a blood or urine sample, explain how the sample will be used and when and how test results will be shared.

Section

2

Effective ways to communicate with Holocaust Survivors include, but are not limited to:

- **Empathetic statements** – Let patients feel they are understood, emotionally supported and safe.
- **Validation** – Assure patients that they are being heard and confirm that their message is of value and being taken seriously.
- **Open-ended questions** – Invite and allow patients to share information rather than replying with “yes” or “no” answers, as simple responses are devoid of detail and valuable information, which may prevent a full understanding of patients’ situations.
- **Reflective statements** – Show patients your level of understanding.
- **Paraphrasing** – Allow listeners (clinicians) and speakers (patients) to verify information discussed to clear up potential misunderstandings.
- **Gentle probing** – Suggest further discussion to gather additional essential information.
- **Tone of voice** – Speak calmly and with kindness, because how you communicate is often more powerful than what you say.

Active listening approaches include, but are not limited to:

- **Attention to total meaning** – Emotional content is especially important; at times it may offer more insight than verbal responses.
- **Noted cues** – Observe nonverbal behavior to gain the “total picture.”
- **Varied responses** – Verbal and body languages may best emphasize engagement, ranging from paraphrasing and silence to gestures.
- **Being honest** – Acknowledge when clarification or re-explanation is needed.
- **Vocal empathy** – Avoid phrases such as “I know how you feel.” Although mostly well-intentioned, such statements are often perceived as patronizing.



Section

3

Manifestations of Post-Traumatic Stress Disorder (PTSD)³

Exposure to traumatic experiences has been associated with full or partial symptoms of post-traumatic stress disorder (PTSD), depression, panic disorder, generalized anxiety disorder and substance abuse. Holocaust survivors at the end of life may respond and react differently than other patients to everyday activities, sounds, conversations and experiences.

This section focuses on the following triggers:

- Memories of traumas and suffering endured
- Personal hygiene
- Dehumanization
- Lack of personal safety
- Disclosure of personal information
- Prospect of approaching death

³ Caring for Aging Survivors of the Holocaust. (Toronto: Baycrest.org) p. 52-59.

Section

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Triggers/Symptoms

Impact of Trauma – It is generally accepted that the greater the exposure to past traumatic events, the greater the probability of future struggles with depression. Traumatic experiences have also been associated with somatic symptoms and physical conditions like chronic pain syndrome, hypertension, insomnia, asthma and cardiovascular problems. While aging Holocaust survivors might not explicitly talk about their traumatic past, they may express many somatic complaints, which need to be understood as manifestations of both emotional and physical (somatic) traumas.⁴

Potential Triggers

Personal hygiene – Harsh smells, showering, inhalation masks and being handled roughly can provoke flashbacks of being pushed and beaten, delousing procedures, horrific “medical” experiments conducted on camp inmates and even the poisonous gas that was piped into communal “showers” (that is, the gas chambers).

Dehumanization – Clinically necessary shaving, identification bracelets, pre-surgical markings, pre-procedural line-ups in holding areas and lack of privacy can be reminders of past losses of dignity, individuality and personhood.

Lack of personal safety – Dogs, alarms, loudspeakers and loud voices were all part of the attacks and intimidation used against those imprisoned in the camps. Religious symbols, like crucifixes, can unsettle Jewish patients. Distrust of the medical community is based on memories of “selections” (for death) and human experiments performed by Nazi “doctors” in the concentration camps. In the camps, exhibiting any pathology could bring about being immediately killed. Separation from family members can be terrifying because during the war years, family members were forcibly separated, never to meet again.

Disclosure of personal information – Refusal to share any personal, financial or clinical information is based on deep mistrust towards anyone who is not immediate family. Advance care planning—contemplating, evaluating, discussing and implementing one’s wishes for future medical interventions and/or end-of-life decisions—is counter-intuitive to the will required to “live” and “survive” during the war years.

⁴ Felsen, I. (2012). Trauma, aging and implications for treatment: When Holocaust survivors need our help most [PowerPoint slides].

Section

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Post-Traumatic Stress Disorder Clusters

According to Irit Felsen,⁵ familiarity with the symptoms of PTSD can enhance compassionate care.

Signs include, but are not limited to, the following:

Re-experiencing of trauma – It is manifested by unbidden memories, including flashbacks, that intrude on awareness in waking hours and in nightmares during sleep, often triggering irrational or exaggerated reactions to non-threatening stimuli.

Avoidance – Patients may resort to withdrawal from relationships and activities that might otherwise have been sources of solace. Such refusals to participate and be comforted might be perceived as negative and can easily frustrate caregivers and family members.

Numbing – Often misunderstood as emotional remoteness or lack of engagement resulting from suppression of trauma-related memories that are too difficult to bear, rendering a person numb.

Hyper-arousal – An important aspect of the “survivor syndrome,” it manifests as chronic anxiety, depression, guilt and sleep disturbances. It is evidenced by high levels of hyper-vigilance, irritability, exaggerated startle response, explosive reactions and intrusive or micro-managerial behavior patterns.



⁵ Felsen, I. (2012). Trauma, aging and implications for treatment: When Holocaust survivors need our help most [PowerPoint slides].

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Intergenerational Communication

A 2011 survey conducted by MJHS Hospice and Palliative Care revealed the following themes:

- Survivors do not talk about their health care wishes with their children, yet rely heavily on them for decision-making.
- Most do not have advance directives in place.
- Children of survivors do not want to “upset” their parents, so they avoid certain topics of conversation, such as advance care planning.
- Caregiver burden is enormous.
- Children of survivors are often overly protective of their parents.

Children, and to some extent even grandchildren, of Holocaust survivors often deeply identify with their loved ones’ pain and losses. They feel responsible for protecting their aging relatives from further suffering. They often express deep commitment and obligation toward the parents, starting at an early age.⁶

How the health care professional can explain the importance of advance care planning to Holocaust survivors:

a. Benefits to the Holocaust survivor:

- You retain control over your health care choices.
- Your values will be reflected in your choices.
- You will reduce the burden on your trusted health care agents (e.g. your children).
- Planning in advance avoids crisis decision-making.

b. Points to stress to the Holocaust survivor:

- You can change your choices at any time.
- A Health Care Proxy is only used IF YOU CANNOT speak for yourself.
- If you do not designate someone you trust to make decisions for you, someone you don’t know might make those decisions for you (e.g. Family Health Care Decision Act [FHCDA, 2010]).

⁶ Wardi, D. (1994). Bonding and separateness, two major factors in the relations between Holocaust survivors and their children. *Clinical Gerontologist: The Journal of Aging and Mental Health*, 14(3), 119-131. https://doi.org/10.1300/J018v14n03_11

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- c. **Benefit to the Second Generation caregiver includes feeling empowered to carry out your parent's wishes without guilt or second guessing.**

**Family caregiving challenges:**

- Geographically distant family caregivers
- Multiple family caregivers—insufficient coordination and/or interfamily conflict
- The Holocaust survivor has no family
- The Holocaust survivor is estranged from family members
- Complex family dynamics, including avoidance of advance care planning conversations
- Caregiver burden and burnout

Different Responses in Holocaust Families

Themes of intergenerational transmission of trauma can be prevalent, clearly demonstrating implicit identification with the traumatized parents. Some themes expressed by children of Holocaust survivors related to the need to protect their parents include avoidance of conflict on the part of the children, difficulty putting their own needs ahead of the parents' needs, and a wish for greater autonomy from the parents. Conversely, some children of Holocaust survivors wish for greater closeness with their parents who, though extremely devoted, are emotionally unavailable—either emotionally distant or over-reactive—so that real and open communication is impossible.

Compounding this turmoil is the ongoing conspiracy of silence as a learned pattern of non-communication between Holocaust survivor parents and the Second Generation. The majority of Holocaust survivors who have reached old age are not afraid of natural death—but their children are. Adult children of survivors might feel profoundly distraught, desperate, guilty, angry and helpless when facing the reality of aging and ailing Holocaust parents. End-of-life conversations are particularly difficult for these children as they are aware of the extreme odds their parents have already overcome to stay alive.⁷

⁷ Wardi, D. (1994). Bonding and separateness, two major factors in the relations between Holocaust survivors and their children. *Clinical Gerontologist: The Journal of Aging and Mental Health*, 14(3), 119-131. https://doi.org/10.1300/J018v14n03_11

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Four Typologies

Four types⁸ of Holocaust survivors and their families, which differ in their styles of adaptation have been identified.⁹ Just as each differently impacts the children in these families, so too are the aspects of transmission of parental trauma to the Second Generation varied.

Types One and Two

The “victim” or “numb” type may tend to transmit anxiety, silence and lack of openness to relationships outside the family. They may also exhibit paranoid reactions to seemingly non-threatening stimuli.



Types Three and Four

The “fighter” or “I made it” type may transmit the need for over-achievement, social activism, toughness or a “take no prisoner” attitude in order to live life to the fullest.

For example: Mrs. M. is a “fighter.” She lived her life to the fullest every day, with very little down time; became a larger-than-life figure to her sons and had a complicated relationship with them; wrote a book about her war experiences; and was very involved in organizations, synagogues and schools.

After Mrs. M.’s admission to hospice care, a social worker helped her accept her diagnosis. Mrs. M. embraced it as a natural process and was ready to live out her life cycle in peace.

Mrs. M. resented it when community leaders and rabbis visited and told her that she had survived before and would be fine now. When her son, who lived on the West Coast, asked her to wait so he and his family could say a proper “goodbye,” she offered to oblige. At Mrs. M.’s funeral, this son said his mother had always given him a lot of freedom; yet, he added, he often felt suffocated in her presence.

⁸ Hantman, S., & Solomon, Z. (2007). Recurrent trauma: Holocaust survivors cope with aging and cancer. *Soc Psychiatry and Psychiatric Epidemiology*, 42(3), 396-402. <https://doi.org/10.1007/s00127-007-0177-0>.

⁹ Danieli Y. (1981). Differing adaptational styles in families of survivors of the Nazi Holocaust. *Children Today*, 10(5), 6-10, 34-35.

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Family Complications

“It is said that members of the Second Generation become ‘memorial candles’ to their parents and their murdered relatives, carrying with them unconscious aspects and identifying themselves with dead relatives.”¹⁰

This dynamic adds a burden of responsibility and guilt and complicates natural processes of development, which propel adolescents to separate, rebel, experiment and develop independent identities.

Issues of Separation

At every significant life transition, the Second Generation faces numerous additional conflicts around issues of separation and individuation. Reaching adulthood and establishing their own families and dual loyalties—with survivor parents on one side and a spouse, plus children on the other—can often create conflicts. For the maturing Second Generation, confronting the aging process of parents, making health care decisions on their behalf and preparing for their inevitable death bring about a realistic need for role reversal. These changes intensify the responsibilities borne by the Second Generation and can lead to anxious and desperate behavior by the adult children in their attempt to protect the aging parent. It might also be perceived as a huge burden and may foster resentment of the survivor parents by the Second Generation.

Members of the Second Generation are vicariously surrounded by death throughout their lives. Yet, they have never witnessed or experienced the actual death of an aging relative since most grew up without a circle of extended family, like grandparents, uncles, aunts, etc. “Letting go” and mourning are foreign concepts and are overwhelmingly difficult in families of Holocaust survivors. Instead of accepting natural death as part of the life cycle, it is experienced in the subjective context of traumatic loss.

¹⁰ Wardi, D. (1994). Bonding and separateness, two major factors in the relations between Holocaust survivors and their children. *Clinical Gerontologist: The Journal of Aging and Mental Health*, 14(3), 119-131. https://doi.org/10.1300/J018v14n03_11

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Reactions of Health Care Providers to Difficult Behaviors

Health care professionals and caregivers must be educated and remain aware of the Holocaust trauma and the impact of PTSD.

The Holocaust was a span of years and an era in history marked by darkness and horror. The mass murder of six million individuals during the Holocaust has become the symbol of atrocity and merciless dehumanization. Today, the sadistic acts that were carried out against millions elicit reactions of total disgust, and even disbelief. Because these atrocities have been documented and described in first-person testimonies—both by the Holocaust survivors and the perpetrators—we know that they did, indeed, take place. Learning of such extremes of torture and humiliation is so difficult to bear, let alone understand, that clinicians might consciously and unconsciously attempt to deny it.¹¹

Responses to be Avoided

Superiority – By acknowledging that the Nazis were capable of such cruelty and sadism, it is understandable that clinicians might think that they have nothing in common with such inhumane people. However, the Nazi perpetrators were not uncivilized “barbarians” or criminals. They were, in fact, a lot like “us.” Many of the elite Nazi leadership figures included highly educated professionals, such as physicians.

Irrelevance – Another way to deal with the difficult reality of the Holocaust is to find reasons to deny the idea that such atrocities could be committed today. Clinicians may try to rationally explain why it is impossible for such inhumanity to reoccur and to conclude that the Holocaust is of no relevance to our contemporary lives, or the future.

Judging – When faced with the survivors of atrocities, some clinicians might find reasons to “blame the victims.” This offers the possibility of preserving a sense of justice, order and security and to deny the idea of such potential dangers being repeated. Clinicians might also (consciously and unconsciously) direct anger at Nazi victims for presenting such a disturbing reality, which might lead them to avoid or reject survivors.

¹¹ Felsen, I. (2012). Trauma, aging and implications for treatment: When Holocaust survivors need our help most [PowerPoint slides].

¹² Robert Jay Lifton has worked as a teacher, lecturer and researcher at the Washington School of Psychiatry, Harvard Medical School, and the John Jay College of Criminal Justice, where he helped found the Center for the Study of Human Violence. Dr. Lifton is the author of many books, including *The Nazi Doctors and Death in Life and Survivors of Hiroshima*, the latter of which won the National Book Award. He studied, lectured and wrote about how individuals coped under conditions of extreme war, torture and genocide. Source: Robert Jay Lifton – Nazi doctors T-4 was the code word for the Hitler’s Euthanasia program. It was named T-4 because the Euthanasia program was directed from an unassuming address that was a confiscated Jewish home in Berlin on Tiergarten Street #4 (hence T-4)



Doubling – Coined by Robert Jay Lifton,¹² it is the process that allowed Nazi doctors in Auschwitz to do the diabolical things they did in the concentration camp and yet continue to view themselves as humane physicians, husbands and fathers outside the camp. The important conclusion from Lifton’s study of Nazi doctors who committed war crimes is that there are situations in which even a person without sociopathic tendencies—and who is not innately evil—can participate in atrocities without experiencing emotional distress. Lifton’s work is documented in his work on “Nazi Doctors,” an in-depth study of how medical professionals rationalized their participation in the Holocaust from the early stages of the T-4 Euthanasia Program¹³ to extermination camps. It was doctors, we now know, who murdered those considered to be physically or mentally handicapped. These people were killed by medication, starvation or in gas chambers from 1939–1945.

Most relevant to our work as medical professionals is Lifton’s observation that doctors (and other medical professionals) may be even more susceptible to doubling than others. In what he calls “medical doubling,” a “medical self” is developed in order to be able to tolerate the repeated encounter with death and suffering and to deal effectively with the many difficult aspects of the job. Optimally, a medical professional does maintain the capacity to be warm and humane by keeping the necessary doubling to a minimum. However, a caregiver must guard against this tendency, a basically adaptive attempt to defend the self from difficult experiences, to become hardened to the pain of the patient or to become detached from the patient’s humanity.

¹³ Source: Robert Jay Lifton – Nazi doctors T-4 was the code word for the Hitler’s Euthanasia program. It was named T-4 because the Euthanasia program was directed from an unassuming address that was a confiscated Jewish home in Berlin on Tiergarten Street #4 (hence T-4)

Section

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Recommendations for health care providers

1. Be cognizant of your own history and experience of personal trauma so you remain sensitive to the experience of others. Sometimes, when clinicians suffered trauma in their personal history, it can be more difficult for them to recognize trauma in others and respond compassionately. The clinicians might not want to be reminded of their own trauma or may feel that their trauma was worse than the patient's.
2. Maintain professional boundaries. Adhere to the highest ethical standards of care and best practices to avoid comparing your own pain to the patient's.
3. Be tolerant of others. See each patient as an individual and equal, rather than a victim or someone "other."
4. Be aware of the tendency to become desensitized to trauma when dealing with pain and suffering as part of your daily professional experiences. Resist this tendency and remain compassionate as well as sensitive to the pain of patients and families.
5. When working with Holocaust survivors or their children, speak calmly and patiently and ensure the content of what you are saying is understood.
6. When you interview or examine patients, establish a sense of trust and personal safety by explaining what you are doing and why.
7. When physically handling patients, be aware of how you touch and move them. Avoid hard and harsh handling. Try to be slower and gentler.
8. When patients seem to be in pain or uncomfortable, let them feel that they are not being ignored and that you are trying to address their pain or discomfort. They might be remembering times when others were indifferent to their suffering.
9. To help minimize medical doubling and the inevitable distancing that occurs with very difficult and needy patients, clinicians must always recognize the patients' humanity and identity—such as their profession, family life, hobbies and other interests. Photographs of patients when they were young and healthy, or with spouses and young children, are powerful reminders of their humanity and of the time when they were most "like us." Looking at photographs on the wall by the patient's bed or on the bedside is an important and powerful act which can block the unconscious tendency to regard a patient as "a case."

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10. Be cognizant of your verbal and body languages when learning that your patient faced horrible atrocities at the hands of other human beings. The temptation to deny or minimize the trauma, or to reject the victim, may be an attempt to protect yourself from this terrible knowledge. Such responses are often driven by adaptive and self-protective behaviors but may prevent you from treating your patients with the care and dignity they deserve.
11. While there is documentation describing barbaric and dehumanizing acts on war victims during the Holocaust, America has its own history of human medical experimentation (e.g. Tuskegee Syphilis experiments—a 40-year study conducted by the U.S. Public Health Service).

Commentary

Clinicians must learn to resist processes and tendencies that can lead a good professional to behave inhumanely. Left unchecked, all of us are capable of participating in atrocities. We are duty-bound to treat our patients as no less human than ourselves.



Section

7

Case Study on Dual Loyalties

About the Family



Mr. D. is a Holocaust survivor and Orthodox Jew. He has been hospitalized in a major New York City hospital several times in the past few months. Mr. D.'s wife, also a Holocaust survivor, is the primary caregiver, although she herself has multiple ailments and is in declining health. The couple has two adult married daughters—one lives in the same building and one lives out-of-state.

The Second Generation daughters accept the hospital social worker's recommendation for community-based hospice care services, as long as the

words "palliative care" and "hospice" are not used in conversations with their parents. The daughters want to keep them at home and avoid future rehospitalizations.

An MJHS Hospice nurse is sent to the home to do an evaluation. Because the patients are Jewish Orthodox and Holocaust survivors, a rabbinic pastoral care provider participates in the visit to help create a stronger level of trust and confidence in the care team. As promised to the daughters, the nurse does not use the words "hospice" or "palliative care" in the evaluation process. Mr. and Mrs. D. sign on as patients.

The daughters are satisfied that their parents are receiving the best care possible. They are also happy that they are protecting their parents from the reality and severity of their individual diagnoses. Shortly after her admission to hospice care, Mrs. D. begins to further decline.

At the next family visit, the social worker **urges the daughters to have an open discussion about the mother's condition with both parents.** The daughters decline again, convinced that they are acting in the best interest of their parents who consequently "might lose hope." Mr. D. wonders aloud who all these clinicians are who visit more frequently now and suggests that his wife of 64 years go back to the hospital to "get fixed like the last time she went."

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Mrs. D. declines further, and once again the social worker recommends an open family discussion, to which **the daughters finally agree**. Alas, 24 hours after that conversation, Mrs. D. dies. As it turns out, Mr. D. had overheard talk in the hospital and **has known all along** that the care delivered in the home to both him and his wife is hospice care. He kept this information to himself lest he burden both his wife and their daughters. Now he is regretful that he was not part of the decision-making process for his wife's care and, worse, **was denied the chance to prepare himself for her death and say a proper good-bye**.

Observations

Mr. and Mrs. D. each received excellent clinical care (Mrs. D. died peacefully and pain-free at home). The Second Generation daughters are grateful for the care their mother received and their father continues to receive as a community-based hospice patient. Yet, this case also presents a learning opportunity for clinical caregivers.

As is typical of the Second Generation, both daughters felt a need to protect their parents from knowing the seriousness of their medical conditions and, therefore, did not discuss the clinical reality that was obvious to all. The daughters also feared that their parents would break down because the diagnoses would be too difficult to accept. **Fear and good intentions delayed an important conversation.**

The daughters of these two Holocaust survivor patients projected their own anxieties about their parents' dying, although the parents themselves did not not fear their own death after having survived against odds and lived long and full lives. Like many other children of Holocaust survivors, they have not experienced the natural death of grandparents, aunts and uncles and are not cognizant of their own difficulties with the anticipated and real loss of their parents who fought so hard to stay alive during the Holocaust years. This conspiracy of silence, though well-intentioned, denies this Holocaust survivor family opportunities for meaningful last conversations and the experience of facing a parent's death together. In retrospect, all wish they had talked earlier.

Important and practical topics that emerge from this case study:

1. Truth-telling
2. Disclosure of information about patient's condition to family and friends
3. Issues of privacy and trust
4. Intervening in a client's life
5. Facilitating conversations between the patient, family and health care providers

Section

7

Update: The second death experience within this family.

After his wife's death, Mr. D. rallies and is discharged from hospice care; he receives home care services for a while and community palliative care. After another noticeable decline, his daughters reach out again to MJHS Hospice, still questioning whether they should tell their father the truth about his current situation. In the same breath, however, **the daughters also state that they want to be honest and transparent with him**, which we encourage and promise to support throughout our service delivery. Mr. D. is being admitted once again to home hospice services. The daughters' new insights offer them the opportunity to allow them, their children, and extended family to **spend meaningful time with their patriarch, cherishing memories of the past and preparing together for the inevitable final farewell.**

Questions for reflection:

- How might you address the daughters' protectiveness?
- How might you assess the patient's understanding of his medical situation?
- What bereavement issues might arise and how might you address them?
- What challenges in your own practice does the vignette bring to mind?
- What might be some of your own personal challenges in working with patients facing the end of life?
- What should you do when the patient has no immediate family and denies the need for medical attention?
- When is the right time to address observable changes/declines in a patient's health condition?
- What tools and strategies might you use to intervene effectively?
- What information might you need to be comfortable making referrals for patients?
- How are issues of bereavement and complicated grief dealt with among social workers and health care providers on the one hand and surviving spouses and children on the other?

MJHS Hospice offers pre-and post-bereavement support for children of survivors. Conversations with trained therapists help adult children become cognizant of their own issues with actual or anticipated loss. Individual and group sessions are particularly helpful to adult children who are protective of their parents—the same parents who endured unspeakable traumas and defied death during World War II.

For more information on how MJHS Hospice cares for Holocaust survivors, please call 1-800-HOSPICE.



Section

8

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Aryeh Rubin and Family

Targum Shlishi Foundation

Irit Felsen, Ph. D., Clinical Psychologist and Trauma Specialist

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