Holocaust Survivors Care Guide

Baycrest

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Introduction

The Purpose of this Manual

Caring for Aging Survivors of the Holocaust has been designed to educate and sensitize all people who care for elderly Survivors of the Holocaust. This material is intended to support family members, health care professionals and varied support staff in the challenging and rewarding tasks involved in ensuring optimum care for aging Survivors. It cannot be overstated enough that it is important to learn about the Survivors' losses while at the same time never forgetting to celebrate their lives. Working with aging Holocaust Survivors is a challenge and a privilege that requires knowledge and sensitivity. Working with Survivors of the Holocaust allows us to witness the indefinable potential of the human spirit and its resilient nature. This work pushes all of us a little further and brings us a little closer to conceiving the inconceivable and to understanding how these men and women endured the unendurable.

As we respond to the ever-changing needs of the Survivors of the Holocaust, we are also learning of relevant connections to the needs of all survivors of genocide. Tragically, other cultures and countries have also been victims of genocide since the Nazi Holocaust. It is imperative that individuals working with aging Jewish Survivors share both their knowledge and their resources with these other communities. While we cannot prevent the fact of genocide, we can participate in the support and healing of all Survivors.

Over the last half century since Liberation, Survivors, their families and caregivers have had time to rebuild, regroup and reassess the care needs of their various life stages. This manual focuses on the aging Survivors of the Holocaust, with the recognition that this work will also evolve and individualize to other groups and communities.

Recognizing the uniqueness of this clientele, their extreme age and extreme exposure to violence helps us understand the need for an individualized response to individual needs. Employing creative responses with this population is not an option but a necessity. It is a unique opportunity to blend theory with practice that will benefit service providers, the community and ultimately the Survivors of the Holocaust.

Family members and health care providers have commented that they need contextual and practical information about how to handle challenging situations with survivors. The most effective way to respond to the needs of this diverse group is to learn about the range of experiences and trauma that Survivors experienced and then provide compassionate, sensitive and individualized care.

Specialized training in the care of people who lived through the Holocaust is the key to quality care. This manual can be read in sections, according to each reader's area of interest. Alternatively, agencies and service providers may want to use the manual to develop an in-service program, possibly reproducing portions of the text as handout material. Someone knowledgeable about providing care to aging Survivors should facilitate in-service sessions. The topic headings can assist in the development of a training curriculum.

What is the Holocaust?

The term Holocaust refers to the extermination of six million Jews during the Nazi era (1933-45). Nazi policy was to systematically and meticulously to erase the Jewish race while the world stood by and did nothing to stop it. Every Jew in Nazi-occupied Europe - which included all European countries except England and Sweden - was doomed to die.

Hitler's war against the Jews consisted of three distinct stages, beginning with the Nazi Party's rise to power in 1933 and the first stage of "The Final Solution of the Jewish Question". This stage of persecution lasted until the onset of World War II in 1939. There were strict laws for Jewish people. Jews were ousted from civil-service positions, deprived of their livelihood, and prevented from attending public schools.

The middle phase of the destruction of Europe's Jewry began with the Nazi conquest of Poland on September 1, 1939, and lasted until the German invasion of the Soviet Union in 1941. Jews were made into outcasts of society and interned in ghettos, where they were isolated from the rest of the population during this period of violence and murder. Thousands died daily as the result of being overworked as slave labour for German war industries, and also because of severe overcrowding, substandard sanitary conditions, diseases, cold, beatings and torture, constant hunger and starvation and medical experimentation.

The last stage of the "Final Solution" began in 1941 after Germany invaded the Soviet Union and lasted until the end of the war in May 1945. This period was marked by liquidation of the ghettos, mass executions, and deportations to death camps which affected Jews from all countries in Nazi-occupied Europe. With the massive destruction of European Jewry came the demise of the 1,000-year-old East European Jewish civilization. Entire Jewish communities were wiped out and their culture lost. Gone forever were Jewish homes, synagogues, commercial and educational institutions.

Who are the Survivors?

Holocaust Survivors are Jews who survived the "Final Solution" and outlived the Nazi extermination program. They were miraculously found alive by the allied liberation forces in 1945. While many Survivors had experienced internment in Nazi concentration camps and death camps, there were other hellish environments from which Survivors emerged at the time of liberation. These included hiding places, sometimes not larger than a closet in an apartment or a haystack in a barn. Others survived by hiding and living in forests as partisan fighters. Some managed to stay alive by concealing their identities and trying to pass as non-Jews or Gentiles. Recognition is given to those courageous 'Righteous Gentiles' who literally risked their lives and their families' lives by hiding Jews or providing them safe harbour.

Of the nearly 8.9 million Jews living in Europe prior to World War II, it is estimated that just 400,000 to 500,000 survived after living in ghettos, being hidden, or working in slave labour camps. It is estimated that no more than 75,000 European Jews survived life in the Nazi concentration camps.

Mrs. B.'s Story

Mrs. B. was one of 12 children who grew up in Viersbenik, Poland. Her family lived in this small town with a few dozen other Jewish families along side the Poles. Most of her siblings moved to North

America in the 1930s. Mrs. B. married in 1937. On September 1, 1939, she was working in her store when the Germans invaded Poland. Bombs were dropped on her town and one landed next to her store. Mrs. B. remembers German soldiers marching through the streets and looting stores, including hers. She lived in a Jewish ghetto until 1942. After that she worked for two years in a sawdust mill on a machine that made stretchers for German soldiers.

Mrs. B. gave birth to a son in 1941. When her son was one-and-a-half, a young Polish girl came to her house and said, "What a beautiful child." Mrs. B. replied, "You like him, take him," knowing that the child would not survive if he remained with her. He was taken 60 miles through the forest but cried so loudly, he was given away to a Polish beggar. The toddler was left in a park, and was found - cold and hungry - by a policeman who took him to an orphanage at a church.

In mid 1944, Mrs. B. was deported to Starachowice where fellow inmates were forced to dig their own graves. Her life was spared and in August, she was deported again -- to Auschwitz. At selection, she learned that she had been placed in a line of those to be gassed. She survived only by leaving her place in this doomed line and joining a different line of prisoners. In late 1944, she walked hundreds of miles in the snow to the camp at Bergen Belsen where she was badly beaten.

Mrs. B. was liberated on April 15, 1945. She learned that her husband had joined a partisan group of 421 fighters and was one of 402 people killed in the forest. The Nazis also murdered her parents and one sister.

After the war, she was reunited with her son who was by then six years old. 6. Mrs. B. recognized him because of a scar and a wart. She married her second husband in 1946, came to Canada in 1948 and gave birth to a second son in 1951.

Caring for Aging Survivors

It is important to understand both the historical events that occurred and the population who survived in order to care for them as compassionately and as caringly as possible. Survivors share a memory of loss and trauma, but each is an individual with his or her own unique and often extraordinary Holocaust experience to relate. This diversity of experience makes it especially challenging to care for Survivors. We must also recognize that each person has had a particular post-War life experience, and is now coping with the aging process.

Throughout this manual, we remind you to keep the following in mind:

Every survivor of the Holocaust is unique. Each person has lived an individual life - including unique experiences and personalities - before, during and after World War II. They come from different countries and cultures. While some lived urban lives, others came from rural settings. While they share a history of persecution, they have different levels of religious observance, speak different languages, and adopted different countries after the War. Each person rebuilt his or her live in different ways. Their diversity reflects the diversity of all Jews, and while the Holocaust may have been the defining traumatic experience of their lives, it is their individual strengths and histories that must always be honoured.

Not all Survivors of the Holocaust were in concentration camps.Many Holocaust Survivors' survived by hiding in forests or being protected by righteous Gentiles. Others may have lived for years as non-Jews with false papers. Still others were confined in ghettos. Some may have survived after being deported from one concentration camp to the next. For most, a sense of personal safety was unknown, and life was lived day by day with the knowledge they could be murdered at any time. These people are alive today through luck and random circumstance, each having "survived" their horrific experiences in different ways.

Experiences before, during and after the war has formed who Survivors are today. This is why even though aging Survivors must now accept help from others, they will respond to this help and to the people who provide it in different ways. What may be difficult or even trigger traumatic memories for one Survivor will not be problematic for another.

Coping skills of Survivors may differ. Some Survivors coped exceptionally well after the War as they were absorbed in starting over. Others experienced more difficulties. But as these people age, long-standing coping mechanisms and resiliency may no longer serve them as well as they once did.

Basic trust was destroyed. Survivors remember all too well a world that betrayed their trust in humanity. As they age and must depend on others for care, they must find some way to trust again. This is a major obstacle faced by those of us who provide care to this group of people.

The Holocaust Resource Project at Baycrest Centre for Geriatric Care is committed to ensuring optimum care for elderly Survivors of the Holocaust and their descendants. We acknowledge that the needs of Survivors are constantly changing as we learn from them and their caregivers. We respectfully request that the users of this manual join us in our efforts to keep it relevant by sharing new information and material as it becomes available. Care providers at Baycrest are committed to maintaining communication with our colleagues around the world. Together, we can ensure comprehensive care that respects the dignity of Survivors.

Mrs. W.'s Story

Born in Majdam, a village in Yugoslavia, Mrs. W. had experienced anti-Semitism as a child. She had to leave school because of her religion. In 1941, at age 21, she was forced to live with her parents and two brothers in one small room in the Sentesh ghetto. There she was able to work as a dental technician for a short time until she was deported to Auschwitz with other members of her family. On the train to Auschwitz she heard her cousin's young daughter say, "Mommy, I'm hungry. I'm cold." The SS guard replied, "Tomorrow, you won't have to worry about that." Upon their arrival to the concentration camp, many of her relatives were immediately sent to the gas chambers.

She was soon transferred to Ravensberg where she was given a uniform with the number 4624. Later, she went to Berlin and spent many months there starving. When the Russians bombed Berlin, the Germans forced Mrs. W. and others to march for two weeks without food or shelter. She was liberated in May 1945 and immediately taken to hospital where she was treated for starvation.

After the war, Mrs. W. discovered that her parents had been murdered in Auschwitz. She did reunite with her brothers who had survived the war in hiding. She married in 1946 and had one son in Europe. The family moved to Canada in 1959.

The Child Survivors

More than one-and-a-half million children died in the Holocaust. Young children were often the first to be murdered, as they could not contribute to the economy and were seen as expendable. The majority of those children who survived were hidden in private homes, hospitals, orphanages or convents by righteous Gentiles. Today Child Survivors are defined as those individuals who survived the War and were 16 years of age or younger at Liberation. Today the eldest of these children are in their 70s, and the youngest are reaching their 60s. They are part of a generation that assumes longevity and thus are considered "young-old."

Relatively fewer studies have been done on these Child Survivors. They only came together in the late 1980s to form an international Federation to discuss their commonalities, differences, and struggles and to explore the impact of the Holocaust on their young lives. For years they were told they were "lucky", either because they were too young to remember the horrors of war, or because while hiding, they did not witness the horrors of the Camps. Those Child Survivors who survived concentration camps are rare, but they too were considered fortunate because they were young and therefore had a better chance to live and repair their lives. The Child Survivors listened, and for many years did not have a voice to articulate their stories, their feelings and describe the damage that the Holocaust inflicted on them. With the best of intentions, relatives and caregivers told them to "forget" about their losses, forget about their countries of birth, their languages of origin, forget about their pain and move on. But even when their memories were fragmented, these grown Survivors found they could not forget. They were not so "lucky" after all.

In fact, when Child Survivors tell their stories at annual gatherings, they remember a great deal. Much is being learned about their experience as they reach out to each other to share, study and reflect. Their childhood trauma and how it has affected them differs from the trauma experienced by older survivors. But the impact of this trauma has marked all aspects of their existence.

Since childhood, they have carried the knowledge that they were meant not to exist. Indeed, Child Survivors are "minority within a minority," each one a unique exception to the rule which led so many European children to an early death. They survived a trauma that they cannot comprehend and which cannot be explained, even by the wisest and most experienced of their elders. They look back on the Holocaust through the eyes of children, yet with the knowledge that they were robbed of their childhoods.

It's not always easy for caregivers to recognize Child Survivors. They rarely have tattoos, many do not have accents, many are educated professionals with successful careers in their adopted countries, and many have assimilated into their communities of choice more readily than their elders. Generally they did not marry other Survivors and did not identify with a Survivor community. Today, as adults, their collective voice is growing stronger, and many are speaking to us of their common experiences and perceptions. Research by noted Child Survivors such as psychiatrist Dr. Robert Krell, psychologists Dr. Natan Durst and Dr. Sarah Moscovitz, and social worker Carla Lessing is defining new and different challenges for the Child Survivors. In fact, they can and do remember more than they were ever given credit for. We are also starting to understand the long-lasting impact of being separated from parents at critical developmental stages, of early parental loss and of forced relocation.

They tell stories about children who instinctively re-attached to "new" parent figures, who accepted "new" identities, stories which demonstrate both the resiliency of children and their capacity for survival. Young children who closeted their capacity for attachment and joy and who were denied a child's right to a secure and safe environment are today understanding how the residual feelings from those times have impacted on their ability to function as adults and as parents themselves.

The long-term effects of this assault on childhood are now coming to light. As more and more Child Survivors are beginning to openly disclose their childhood traumas, even more are coming forward and identifying themselves. Their capacity for living full lives underlines the resilience of traumatized children while their ongoing pain and loss emphasizes the need for understanding.

What will the impact of aging be on these Child Survivors? While today the majority are considering retirement and certainly not thinking about long term care options, over the next decade the eldest of their group will almost certainly become consumers of geriatric services. The only given is that they will be very different from the current group of elderly Survivors for whom this manual is designed.

The current Survivors were mostly teenagers and young adults at the onset of the War, and they have memories of a pre-War life. Obviously, there are as many unique memories as there are individuals, but this group was able to rebuild their lives on a foundation of family history, however badly severed such foundations were by the Holocaust.

The Child Survivors have a different perspective on family history, their place in the world and their sense of origin. They were either orphaned and therefore have fragmented or no memory of pre-War days, or else they had parents or relatives who survived and carried their own burdens.

Memories, the ability to remember, and the lack of substantial or concrete pre-War memories are ongoing themes for Child Survivors. Memory - either its presence or absence - is also a crucial component defining the quality of aging. Older adults coping with dementia rely on long-term memory to sustain a sense of self. How will the Child Survivor cope with this challenge? Little is known about the long-term physiological impact of starvation during early childhood, about the lack of exposure to the outdoors and the inability to move and wander freely. How might this affect the physical aging of the Child Survivor? Aging is an emotional and psychological challenge for any individual. Will there be new and as of yet undefined psychological or emotional issues for the Child Survivors as they reach their 80s and 90s?

At this time, Child Survivors, their families, friends and health care professionals must realize that there are more questions than answers. As the majority of Child Survivors age, they will define their issues and, together with their families, decide how best to individualize their needs while sensitizing their health care providers. Many Child Survivors became professional educators, healers and leaders. They, unlike their older counterparts, will lead the discussion and give direction on how best to provide for their needs. Their families, and the health care professionals who look after them, must accept that the care giving issues of tomorrow will be new and different, and as such, will require new and different responses.

Acknowledgements

Two gifted photographers have contributed their talents and brought life to these pages.

Yuri Dojc's images are from a series of over 80 Holocaust Survivors documented by him since 1996 in the Slovak republic. This work is in honour of Survivors everywhere and the millions who did not survive.

Orah Buck has captured the passage of time in the faces of her Baycrest portraits, demonstrating the dignity and resilience of these older Survivors.

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Aging

Aging Holocaust Survivors

From the beginning of the Holocaust, the sick, handicapped and elderly were immediately murdered. Today as Survivors cope with aging bodies and a range of health concerns, many associate old age or weakness as a sign of inevitable hardship or even death. Each individual Holocaust Survivor's response to coping with his or her early life trauma is reflective of his or her special and unique sense of self. All Survivors of the Holocaust, regardless of their specific Holocaust experiences, were exposed to traumatic life experiences.

Now as they are aging, their remarkable coping capacities and resilience, coupled with the challenges of aging, may make this group particularly vulnerable. Survivors who dedicated themselves to hard work, building new lives, new families and new communities may find retirement overwhelming and the prospect of free time both daunting and threatening. Unwanted unstructured time can reduce defenses and allow room for intrusive thoughts and other symptoms of post-traumatic stress disorder. Worrying about the potential need for residential care or actual entry into a nursing home is especially difficult for Survivors. This is not their first experience with the loss of home, family, community, privacy and freedom, and while such a move may be traumatic in itself, it can be reminiscent of early life losses.

As Survivors advance in age and as their health care needs become more complex, they come into contact with hospitals, nursing homes and institutions for the aged. This has the potential to elicit difficult reactions associated with their early life exposure to extreme pain and loss. An example would be Survivors who were involved in Nazi medical experimentation during the war and who react with fear or mistrust to medical care. Even medical environments such as doctor's offices, hospital clinics, and labs may be difficult reminders of early life trauma. Such feelings are likely to persist when an aging or medically frail Survivor confronts the natural course of aging.

Because the process of aging itself can be uniquely challenging for Survivors, it is helpful to understand some of the "normal" changes that occur as we age. It helps if family members and health care workers can distinguish these normal changes from those caused by disease or by an elderly Survivor's traumatic past. This section will discuss normal aging and provide facts about dementia. Tips for communicating with cognitively impaired seniors are also provided here, followed by issues to consider when Survivors lose some of their cognitive abilities. Finally, a section on bereavement points out that loss is a natural part of growing older. At the same time, we must recognize that loss is particularly difficult for those who have experienced so much unnatural loss early in their lives.

“Normal” Changes Associated with Older Aging

Courtesy of Health Canada, Division of Aging and Seniors.

Although diversity is a hallmark of the senior population, there are common normal changes that accompany aging, and even healthy seniors experience losses that can affect their access, level of interest and/or capacity to receive and understand information.

Sensory changes are a normal part of aging. Changes in visual and hearing acuity can affect an older person's capacity to absorb information. Changes are seldom abrupt and may be barely noticeable at first. A person may begin to have difficulty hearing clearly if a sound is above or below a certain pitch or if there is background noise. The capacity to see clearly in low light or shadows may decline, or susceptibility to glare may increase.

Physical changes include declines in flexibility, strength, speed of execution, fine motor control and hand-eye coordination, which can translate into difficulty manipulating controls and small objects (touchtone telephone buttons, automated banking machines and direct payment keypads, coin-operated devices, household appliances). Diseases such as arthritis, rheumatism and osteoporosis can also affect agility and mobility.

Changes in cognitive function, including memory, reasoning and abstract thinking, affect a very small percentage of younger seniors, although the percentage does rise with age. In general, sharp brains tend to stay sharp; cognitive processing may take a little longer, but this is normal aging, not a sign of dementia. Skilful communication (repeating key points in various ways, checking for understanding) can help overcome this.

The social changes surrounding aging include changes in income and earning capacity, loss of social networks through retirement and the death of spouse and/or friends, society's "isolating" attitude toward seniors, the potential for reduced access to transportation and hence to recreational and social activities, and changes in living arrangements.

Finally, aging can bring emotional changes, many of them arising from sensory, physical and social changes. They include loneliness, isolation, tension or worry, anxiety about becoming dependent on others, and fears about safety, security and loss of access to activities or services enjoyed when younger.

Mr. D.'s Story

Mr. D. was born in Hungary and spent the early part of the War years building roads as part of a forced labour battalion. He lived with his parents, two sisters and one brother. His older brother was married and had two young children. In 1944 he was deported to Bergen Belsen concentration camp. His parents were immediately sent to the gas chambers as was one sister, his sister-in-law and his two nephews. He remained in the barracks with his two brothers where they kept one another going, sharing scraps of mouldy bread and planning how they would go to Palestine when the War ended. Mr. D says he could never have survived without his brothers there for moral support. His older brother contracted tuberculosis and died quickly. His younger brother was killed for trying to nurse him. Mr. D. was left alone and was determined to live so that he could tell the world what happened to his family.

When he was liberated, he returned to Budapest to search for any living relatives. Only one sister had survived, and the two made their way to Israel. There Mr. D. met a fellow Hungarian, and they married and emigrated to New York. Their two children were born there. Mr. and Mrs. D. traveled to Israel regularly to visit with his sister. In New York he worked in the construction business and eventually built his own company. He became very successful, and when one of his children moved to Israel, Mr. and Mrs. D. decided to retire there. Mr. D. was always active in Holocaust education and continues to talk to schoolchildren both in New York and Israel. He feels he is honouring his family's memory by doing so.

Dementia

The majority of older adults do not experience incapacitating memory loss or cognitive impairment. Severe memory loss, disorientation, major intellectual changes all signify underlying health concerns and should be investigated. However, a certain degree of memory decline is inevitable as people age. In healthy aging, memory changes are relatively slight, and are largely amenable to compensatory strategies. In contrast to healthy aging, memory disorders such as Alzheimer's disease and related dementias are associated with moderate to severe memory decline.

Dementia is a syndrome consisting of a number of symptoms that include loss of memory, judgment and reasoning, and changes in mood and behaviour. These symptoms may affect a person's ability to function at work, in social relationships or in day-to-day activities. Sometimes symptoms of dementia can be caused by conditions that may be treatable, such as depression, thyroid disease, infections or drug interactions. If the symptoms are not treatable and progress over time, they may be due to damage to the nerve cells in the brain.

Effective Communication in Residential Settings with People Who Have Dementia

Courtesy of Donna Reese

Key pointers for communicating with people who have dementia and live in long-term care settings are:

Introduce yourself when you come into the room. Be courteous; knock first.

Make conversation. Get to know the person better. Conversations about the present can be frustrating; instead, go to a time where he or she is comfortable.

Use reminiscing as a positive tool. The use of memory books - family albums with labeled photos - can increase communication.

Use the name a resident feels comfortable with, perhaps even a maiden name or childhood nickname instead of a formal title.

When performing a task, tell the person what you're going to do, involving her when possible. If you're going to fix her hair, for example, let her hold one end of the comb while you work.

Use nonverbal clues. A resident may no longer understand the meanings of certain words. Instead of just saying, "It's time for dinner," mention how nice dinner smells. When you ask if she'd like to sit down, point to the chair.

Don't rush the person or ask too many questions.

Provide appropriate choices. Maybe you can ask one resident whether she wants to wear the blue dress or the green dress. With another, you might have to say, "How about the red shirt today?" as you hand it to him.

If you are working with a colleague, talk to the resident, not to your co-worker as if the other person weren't there.

Avoid too much outside stimulation, such as a loud TV, while other activities are going on.

Avoid under-stimulating people. In maintaining a sense of calm, don't forget that too little stimulation can be as bad as too much.

Effective Communication in Community Settings with People Who Have Dementia

We often make the assumption that older adults living in their own homes feel safer and more at ease, regardless of functioning level. Even in familiar surroundings, the individual coping with dementia can become disoriented and agitated as circumstances change. Some key pointers that might ease those fears and assist in communication are:

Be respectful of the individual's right to privacy and autonomy. Try and announce visits shortly before arrival and identify yourself and your purpose while knocking. If you are a visiting professional caregiver, it would be best to come with a family member or other known person.

Make conversation. Get to know the person better. Conversations about the present can be frustrating; instead, go to a time where he or she is comfortable. Focus on familiar aspects of the home and home life in order to give the client a sense of control.

Use reminiscing as a positive tool. The use of memory books - family albums with labeled photos - can increase communication. Pictures hanging on the wall, favourite china, familiar foods, and signs of hobbies or special interests can contribute to meaningful and comforting conversation.

Use the name the individual feels comfortable with, perhaps even a maiden name or childhood nickname instead of a formal title. Always ask what name they prefer you use, and try to incorporate and repeat your name in the conversation.

When performing a task, tell the person what you're going to do, involving her when possible. If you're going to fix her hair, for example, let her hold one end of the comb while you work. Wherever possible, consult with the client on how he would prefer things done.ie. which washroom, which towels etc. If choice is difficult or confusing, establish a routine that works and stick with it.

Use nonverbal clues. An individual may no longer understand the meanings of certain words. Wear a nametag, describe what you are doing while you are doing it and establish whether a friendly touch would be appreciated or considered intrusive.

Don't rush the person or ask too many questions.

If you are working with a colleague, talk to the client, not to your co-worker. Always try and include the client in the conversation. If this is impossible structure you conversation so that it would be of interest to the client.

Avoid too much outside stimulation, such as a loud TV, while you are in your client's home. Once again, try and employ different senses such as a lemon scented soap, a differently scented hand lotion, soft music, a warm and comforting shawl etc. Your visits should be punctuated and differentiated from other routines and activities.

Always respect the fact that you are a visitor in your client's home and regardless of cognitive capacity your client should never be made to feel awkward in her own home.

Aging Survivors with Cognitive Loss

Ruth Goodman, MSW, Baycrest Centre - Most older people maintain a sense of continuity and meaning that helps them cope with cognitive and physical changes. It is memory that helps define the present, gives meaning to the past and creates direction for the future. Memories change over time, being reinterpreted in our present social context. Cognitive impairment may change the impact of war trauma by confusing events of the past in time and place.

Survivors with cognitive losses may retain a sense of what happened to them during the War years, of the dispersion of their families, the death of relatives, the immigration to Canada, and the years of adjustment here. The sequence and the balance between the good and the bad may become blurred. Depending on the nature and severity of their cognitive loss, they will experience their functional losses in different ways.

For some, the experiences of the War years have been overshadowed by many years of accomplishments; for others, the loss of family, the experience of being immigrants, of continual readjustments, of not fitting in with the mainstream culture, continues to be part of their consciousness. The adjustments to physical and cognitive losses are experienced within a communal context, which has both restrictive and supportive features.

With increased cognitive losses comes the need for assistance and supervision by others. Becoming dependent on others, having one's vulnerabilities observed can mean different things for Survivors. For some, the sense of security and direct attention given is very reassuring. For others, dependence on others is experienced as an invasion of privacy, or with fear and misperceptions, and care is resisted.

Some of the behaviours often associated with increased cognitive loss, such as hoarding, preoccupation with food, and the need for continual reassurance and information to allay anxieties, may take on additional meaning for Survivors. Caregivers need to be aware of the range of possible meanings of certain behaviours. It is just as important not to ascribe all fearful or demanding behaviours to the Holocaust experience.

Within an institutional setting there are a range of issues to consider. Trust, security, sense of control and autonomy, relationship to authority, and justice and equity are all prominent in the developing relationship between the staff and aging Survivors and their family members. Staff must remember that institutional norms take time to adapt to and may seem very intrusive. The degree of flexibility regarding bathing practices, routines, clinic appointments entailing waiting periods and apprehension, are a few of the areas of institutional life that need thoughtful attention.

Paying attention to their present construction of their social world, and the ways in which Survivors themselves make connections to their earlier experiences, is what is paramount in trying to understand how they are interpreting their day-to-day life in a long-term care facility. Aging Survivors with cognitive loss integrate their War-time experiences into their sense of who they are now, and convey the importance of certain principles which are meaningful to them. It is through the lens of these moral principles that they interpret their relational world now.

Even in the throes of dementia, Survivors are separate and distinct individuals in how they cope and respond. Their continuing relationship with others - family members, caring staff, and other residents - affirms their personhood. Knowing that others are caring about them may provide reassurance and security. For others, such care evokes a sense of loss, a lack of autonomy and loss of control.

Whether Survivors live in an institution or in their own homes, caregivers supporting those with cognitive losses must be aware of the impact of their Holocaust trauma. Do not assume that previous post-War resilience and coping mechanisms will continue as cognitive losses escalate. Increased dependency needs will create a range of emotional reactions that require consistent supportive and reassuring care by caregivers.

Grief and Bereavement

Cindy J. Grief M.D., FRCP(C), Baycrest Centre

Grief and bereavement are terms used interchangeably to describe the emotional suffering that individuals experience after a profound loss. Grief is the ultimate form of disconnection. The ability to connect with the person who has died in a physical, tangible sense is forever lost. For many, the journey of grief means finding a way to connect with a deceased loved one in different, novel ways. For some it means remembering a loved one in a spiritual sense, for others it means recreating the relationship through memories and rituals. While grief is universal, the experience of grieving is unique, influenced by cultural, religious and personal backgrounds. Grief is many-layered and multidimensional. The dimensions affected include those of feelings, thoughts and behaviours.

Survivors have had to live with multiple layers of profound loss ever since the War. Not only did they experience the premature loss of many family members, they have grieved for homes, communities, lifestyles, lost years and their sense of security. In any discussion of grief and Survivors of the Holocaust, it is important to remember that their grief has these added complexities.

Feelings Associated with Grief

- numbness, shock, emptiness
- disbelief, sense of unreality
- profound sadness
- loss of capacity for pleasure and enjoyment
- apathy
- anger, hostility
- guilt
- anxiety
- physical aches and pains
- Thoughts
- endless loops, ruminations about deceased
- intrusive memories of the deceased
- impaired concentration, indecisiveness
- existential questions
- worries about the future
- questioning of spiritual beliefs
- Behaviours
- motor restlessness
- reduced activity, decreased energy
- changes in eating habits
- changes in sleep pattern, insomnia
- increased alcohol use, smoking
- reckless behaviour
- social withdrawal
- changes in social connections

It is important to recognize grief as a normal process following loss. While a person who is grieving may also be depressed, grief is not depression, although the two share overlapping features. The boundary between grief and depression may be hard to distinguish. The characteristic features of grief listed above are also common symptoms of major depression. (Major depression is also referred to as clinical depression.)

Grief vs. Clinical Depression

- among the recently bereaved, a depressed mood is regarded as normal and understandable
- bereaved individuals tend to be able to carry out daily activities
- guilt, feelings of worthlessness and hopelessness are generally less pronounced
- suicidal ideation is less prevalent

If bereaved individuals seek help from physicians it is more likely to be for insomnia or weight loss rather than mood symptoms. However, the distinction is somewhat arbitrary, and clinical depression is a common outcome of bereavement. Bereavement is associated with medical illness as well as psychiatric difficulties. Adverse social outcomes are also observed in the aftermath of significant loss.

What is the Duration of Grief?

Grief has often been conceptualized as a series of stages or phases to be navigated. Increasingly, researchers have come to regard grief as timeless. It is recognized that the experience of the bereaved individual shifts over time as the trauma of the loss is absorbed.

What makes grief timeless?

- feelings oscillate over time, depending on internal and external states
- people adapt to the fact of the loss, but it is ever-present
- there are endless anniversaries, holidays, celebrations and triggers that reactivate grief
- there are many ripples of loss in realms of finance, housing, relationships and also ongoing shifts in social sphere, family structure, personal outlook

Family caregivers of Holocaust Survivors should be aware of the oscillation of grief patterns and consider what particular triggers might be affecting their loved one. The following principles may be useful in supporting those who are grieving.

Give people permission to grieve, whatever the timeline. Some people will have a harder time in the aftermath of loss. This does not mean they are weak or abnormal. Often people stop talking about their deceased loved one as they perceive it is unacceptable to do so according to society. Many will find it a relief to be able to share feelings and memories about a deceased loved one with someone who cares to listen or they may prefer to keep their feelings to themselves. Allow individuals to proceed at their own pace.

People have a right to feel whatever they are feeling. Anger. Guilt. Sadness. Grief is not a contest. It is important to realize we are there to be supportive and not to judge who deserves to feel distressed. There is no point in debating a "hierarchy of pain" with Survivors, since each individual responds to and copes with their own losses as best they can.

Allow people to talk about the circumstances of the death and the deceased if they wish to do so. The bereaved person may prefer to talk about how he or she is feeling or coping, but should not be pressured to talk about the loss. There is often a great deal of pressure as Survivors age to document their stories, to discover untold family history and so on. Remember that people develop their own coping mechanisms that include readiness to discuss war traumas.

Grief is universal, but uniquely experienced and individually expressed. Don't expect the bereaved person to follow an established pattern of mourning. Allow for individual differences. People's grief experiences will be shaped by previous losses, circumstances of the loss, support network, cultural background and a myriad of other factors. Be prepared for fluctuations and oscillations in people's mood and outlook depending on anniversaries. Triggers that elicit grief will differ between individuals.

Help the bereaved person reconnect with life. Bereaved individuals must discover for themselves how to become reengaged with life, regardless of life stage. But you can help them to refine their goals. You can assist them in developing a future orientation, to identify meaning in their lives. Simply being there and listening can be perceived as enormously helpful. Caring is life affirming.

Grief is not always visible. Ask people how they are doing. Don't assume they are okay. People are very good at masking their feelings and become better at doing so over time. Show you care.

Grief and the Holocaust Survivor

Paula David, MSW, Coordinator, Holocaust Resource Project, Baycrest Centre

If grief is profound disconnection, how can individuals connect with others in the aftermath of loss? Some people gain strength from family members and friends, or from the wider community. Some find that their synagogue services offer comfort. Some find attending bereavement groups helpful, although often Survivors find that their multiple levels of loss and years of grieving may overwhelm mainstream bereavement groups. Discussion groups designated specifically for Survivors may provide more comfort.

However, for many people, grief is also an exceptionally isolating experience. How can anyone understand? Family members may be grieving as well, and are therefore less able or unable to provide support. Sadly, many Survivors' families were exterminated during the Holocaust and so there are literally no family members with whom to share the grieving experience that follows the loss of a spouse, an adult child or a close friend, for example. Feelings of grief from recent losses are compounded by those from long ago.

For the Survivor, recent loss can highlight past traumas. Feelings of loneliness and isolation may be magnified by memories of War-time experiences. Often, loss is multi-layered. There are layers of loss to contend with in addition to the death of a loved one. Older Survivors, as part of the normal aging process, are vulnerable to loss of health, including a decline in mobility and memory. For some, the death of spouse might mean being unable to live independently. While still in the midst of grief, individuals may be forced to move into a long-term care facility. While the aging Survivor must cope with layers of loss and grief, so does their family.

As Survivors are facing their mortality, their longstanding losses and their recent losses, their children are now stepping forward to support their parents, to care for them and, eventually, to mourn them. The burden of their parent's grief plus their own anticipatory mourning of parental loss creates a need in many of the second generation to try and "make up" for their parents' losses. This adds an increased burden to these same children, who often experience frustration when they are unable to fulfill this far-reaching and unrealistic task. These children also have to face their parents' mortality. While it is important to recognize and support the grieving process, it is just as important to be aware of what the individual Survivor and her family are grieving about.

Grief, loss and mourning are crucial components of living and also of working with older adults. How staff and families respond to older adults' losses, illnesses and ultimately to their deaths, contributes both to the dignity of the process and the quality of the subsequent bereavement and mourning period. The loss of a parent is traumatic for the child regardless of age.

Families of Holocaust Survivors have fewer resources and less experience with issues of death and dying. It is a paradoxical irony that this group of adult children is intimately familiar with the death of so many, while the death of an elderly parent is shrouded in mystery. Health care staff must be cognizant of the unique sensitivities and vulnerabilities of this group when discussing prognoses, end-of-life directives and bereavement issues in general.

The Nazi Holocaust and the impact it had on the Survivors, their families and humanity in general is a complex and never-ending area of study. The Holocaust is synonymous with visions of multiple deaths and trauma. Today as the last of the Survivors of the Holocaust are coping with the challenges of aging, their adult children are dealing with the issues of death and dying and losing a unique group of people. Adult children of Holocaust Survivors often consider their own family lives and existence in the shadow of the Holocaust in order to continue their parents' commitment to rebuilding shattered families. Regardless of the difficulties faced by adult children of Survivors after their parents' death, they recognize and can articulate their challenges. While their parents' collective sorrow and trauma may be reflected in their world views, so too is their resilience, adaptability and ability to commit to the future.

Historical Overview

Genocide

Courtesy of Israel Charny, Encyclopedia of Genocide.

The mass slaughters of unarmed human beings have tragically taken place very often on our planet. The extermination of a race or people has been termed "genocide", literally meaning "the murder of a people". Past genocides in the 20th Century include:

- the Armenian Genocide at the hands of the Turks
- the Holocaust - of course of the Jews, who were defined by the Nazis as the ultimate nonhumans "deserving" of extermination, but also of the Roma (Gypsies), homosexuals, and others including Jehovah's Witnesses, political opponents, and "plain" civilians in occupied countries, in addition to prisoners of war
- many different nationalities and peoples in the Soviet Union by Stalin
- the Chinese in Manchuria by the Japanese in the 1930s
- various indigenous tribes in a variety of countries, for example, Australia, Brazil and the United States
- Cambodia's killing fields by Pol Pot and the Khmer Rouge
- Burundi and Rwanda in a seesawing series of genocides by two peoples - the Hutu and Tutsi - over many years
- the gassing of Kurds and the destruction of Kurdish village populations in Iraq by Saddam Hussein
- genocidal murders along with forced migration for dreaded "ethnic cleansing" in the former Yugoslavia

This historical overview provides a detailing of the events of the Holocaust - the genocide of the Jewish people.

The Holocaust: Genocide of the Jewish People

Courtesy of the United States Holocaust Memorial Museum, Washington, DC

The Holocaust was the systematic, bureaucratic, state-sponsored persecution and murder of approximately six million Jews by the Nazi regime and its collaborators. "Holocaust" is a word of Greek origin meaning "sacrifice by fire." The Nazis, who came to power in Germany in January 1933, believed that Germans were "racially superior" and that the Jews, deemed "inferior," were "life unworthy of life." During the era of the Holocaust, the Nazis also targeted other groups because of their perceived "racial inferiority".

In 1933, the Jewish population of Europe stood at over nine million. Most European Jews lived in countries that the Third Reich would occupy or influence during World War II. By 1945, close to two out of every three European Jews had been killed as part of the "Final Solution", the Nazi policy to murder the Jews of Europe. Although Jews were the primary victims of Nazi racism, other victims included tens of thousands of Roma (Gypsies). At least 200,000 mentally or physically disabled people were murdered in the Euthanasia Program. As Nazi tyranny spread across Europe, the Nazis persecuted and murdered millions of other people. More than three million Soviet prisoners of war were murdered or died of starvation, disease, neglect, or maltreatment. The Germans targeted the non-Jewish Polish intelligentsia for killing, and deported millions of Polish and Soviet citizens for forced labor in Germany or in occupied Poland. From the earliest years of the Nazi regime, homosexuals and others deemed to be behaving in a socially unacceptable way were persecuted. Thousands of political dissidents (including Communists, Socialists, and trade unionists) and religious dissidents (such as Jehovah's Witnesses) were also targeted. Many of these individuals died as a result of incarceration and maltreatment.

Before beginning the war in 1939, the Nazis established concentration camps to imprison Jews, Roma, other victims of ethnic and racial hatred, and political opponents of Nazism. During the war years, the Nazis and their collaborators created ghettos, transit camps, and forced-labor camps. Following the invasion of the Soviet Union in June 1941, Einsatzgruppen (mobile killing units) carried out mass-murder operations against Jews, Roma, and Soviet state and Communist party officials. These units murdered more than a million Jewish men, women, and children. Between 1942 and 1944, Nazi Germany deported millions more Jews from the occupied territories to extermination camps, where they murdered them in specially developed killing facilities.

In the final months of the war, SS guards forced camp inmates on death marches in an attempt to prevent the Allied liberation of large numbers of prisoners. As Allied forces moved across Europe in a series of offensives on Germany, they began to encounter and liberate concentration camp prisoners, many of whom had survived the death marches. World War II ended in Europe with the unconditional surrender of German armed forces in the west on May 7 and in the east on May 9, 1945.

In the aftermath of the Holocaust, many of the survivors found shelter in displaced persons (DP) camps administered by the Allied powers. Between 1948 and 1951, almost 700,000 Jews emigrated to Israel, including more than two-thirds of the Jewish displaced persons in Europe. Others emigrated to the United States and other nations. The last DP camp closed in 1957. The crimes committed during the Holocaust devastated most European Jewish communities.

Chronology of the Holocaust

The following Chronology gives an overview of the significant dates of the Holocaust. This has been included to give the reader an understanding of how the Holocaust cast its dark shadow across Europe and in what order different countries were affected.

Quality care does not require an historical accuracy, but understanding how history unfolded can help caregivers relate to the individual circumstances of older survivors. If you know something about an individual's background, the chronology may give some insight into when they were deported, whether as slave labourers, to concentration camps or under some other circumstances, and also for how long they may have been incarcerated.

I herewith commission you to carry out all preparations with regard to...a total solution of the Jewish question in those territories of Europe which are under German influence...I furthermore charge you to submit to me as soon as possible a draft showing the...measures already taken for the execution of the intended final solution of the Jewish question.

Source: Hermann Goering's July 31, 1941 directive to Reinhard Heydrich, quoted in William L. Shirer, The Rise and Fall of the Third Reich (New York: Simon & Schuster, 1960), p. 964.

For a timeline click here

Destruction of the Jewish Communities of Europe

Between 1000 AD and 1939 the Jews of Europe, despite constant persecution and hatred by others, maintained their traditional community and family life, including observance of the Holy-days, the keeping of the Sabbath, communal self-help, charity, and the strong encouragement of learning and scholarship and a belief in the common destiny of the Jewish people, to survive as a people.

Between 1933 and 1945, the Nazis not only killed six million Jews, they also systematically destroyed all the Jewish communities of Europe. The flourishing Jewish communities of Warsaw, Riga, Salonika and Amsterdam, just to mention a very few, were completely destroyed. Hundreds of small communities, in all the countries where the Nazis persecuted the Jews, vanished. Those who survived the Holocaust not only lost their families and their homes, they also lost their religious, social and family traditions, and their communities.

Survivors: The Immigrant and Settlement Experience

Harold Troper, Ph.D, Professor of Theory and Policy Studies, University of Toronto

Displaced Persons

With the end of World War II in 1945, most of the tattered remnant of Jews who emerged out of the Holocaust became part of a collectivity known as DPs, Displaced Persons, a term originally coined by United Nations refugee officials to legally designate more than one million individuals, Jews and non-Jews. These people found themselves outside their country of origin at the end of the war and refused to back to go back to their countries of origin. They were without clear status or place to go -- stateless people with too much past and no apparent future. In the popular mind, DPs, Jewish and non-Jewish alike, represented a population as unwanted as it was displaced, uprooted and seedy cast-offs of a horrible war, a potential burden to any country that would admit them.

Mrs. P.'s Story

Mrs. P. married her childhood sweetheart was living in a small town outside Lodz in Poland with her husband and four young children when the family was transported to the Ghetto. Shortly after arriving, her three youngest were shot in front of her and the next day her husband was deported to Auschwitz. She never saw him again. She and her 12-year old daughter managed in the Ghetto for four months. At that time, she used the last of her savings and managed to smuggle her daughter out to the care of a Polish farmer. Two months later Mrs. P. was also sent to Auschwitz. There she was part of slave labour detail, spending half a day hauling large boulders to one side of a field, and then the second half of the day returning them to their original place. She watched women collapse and die all around her. She watched women selected for the gas chambers disappear and never return. Each day she prayed she would die and her suffering would end.

Mrs. P. survived and spent two years in Germany in a displaced person Camp … all alone. One day the Red Cross worker found her and announced that her eldest daughter had been found alive. They were reunited and eventually emigrated to Canada. Neither woman ever told the other the details of their individual tortures, rape, humiliation and pain during the War years. Neither woman let a day go by without speaking to each other … for the next 55 years. Mrs. P.'s daughter married in Canada and had a wonderful loving family, whose accomplishments and presence cushioned some of the pain. Regardless of closeness, good health and growth of the children and grandchildren, both women have a similarly haunted look on their face to this day.

Response to the DPs: The Canadian Example

Of all DPs, the Jews may have been the most problematic. Everywhere, there seemed reluctance to accept Jewish DPs. Canada was no exception. The Canadian response to the European refugee question, worse only by degree than that of the United States and other western countries, was shaped in the pre-War era. A faltering national economy during the 1930s and domestic political considerations -- including anti-immigrant and especially anti-Semitic sentiment --combined to close Canada's doors to Jewish refugees trying to escape Europe. If no single country stood out for its generosity to Jews in need of a haven, in retrospect, Canada had arguably the worst record of any possible haven in the west, in failing to offer Jews safe harbour from the Nazi storm.

Canadian reluctance to permit the entry of Jewish refugees did not end with the Allied victory in 1945, or with the first revelations of the catastrophe that had befallen European Jews. Post-war Canada, its restrictionist immigration regulations still intact, rejected any suggestion that new homes in Canada be offered to any Displaced Persons, least of all to Jews.

In addition to widespread anti-immigrant fears, the Canadian government of the day had to cope with its own fears -- fears that, without the spur of wartime spending, postWar Canada would soon slip back into a 1930s-style economic Depression. If such a return to economic hard times caused jobs to disappear, all the more reason to reject any reopening of Canada's immigration door. But, the government's fears were misplaced. Strong post-War consumer demand, fuelled by capital reserves squirreled away as forced savings during the War, and a seemingly insatiable world appetite for Canadian raw material and manufactured goods, particularly as building-blocks in the American-funded Marshall Plan effort to rebuild war-shattered western Europe, propelled the Canadian economy forward.

Rather than a shortage of jobs, there was soon an unprecedented shortage of labour. Acute domestic labour shortages soon brought intense pressure from labour-intensive industry, calling for an easing of immigration restrictions. The small Jewish community in Canada, mostly made up of former Eastern European immigrants and their children, had none of the electoral clout of the American Jewish community, or the political clout of the older, established and politically influential American Jewish leadership. Nonetheless, it added its voice in favour of a humanitarian renewal of immigration, including the acceptance of Holocaust Survivors. But it was economic self-interest, not humanitarian appeals, that won the day. As the drumbeat from big business grew louder, the government gradually relented. Immigration reopened.

Immigration priority was originally given to preferred immigrants from Britain and western Europe, but demand for labour continued to outstrip supply. Where would more labourers come from? What about the DP labour pool? Industry wanted workers, and there were workers aplenty to be had in the DP camps of Europe. Mindful of the larger Canadian public's apparent antipathy to Jews, but anxious to get the DP immigration ball rolling, the government devised a series of schemes to import thousands of workers to fill waiting jobs in specific industrial sectors. It then quietly advised Canadians administering the European selection process that Jews had no track record in those industries and that any Jewish applicants were to be designated as unsuitable for admission. This ploy proved as effective as it was transparent. As immigration cranked up, Jews were kept out.

Only in late 1947, as immigration of Displaced Persons into Canada was quickly building up a massive head of steam and the Canadian labour market showed no signs of slowing down, did government policy begin to relent on the Jews. After much negotiation, the government agreed to permit 1,000 orphaned Jewish children into Canada under the sponsorship of the Canadian Jewish community. At the behest of the largely Jewish-owned Canadian clothing industry, which also claimed a shortage of skilled labour, the government allowed limited recruitment of clothing and fur workers from among Jewish Displaced persons. In addition, the government gradually enlarged the circle of those eligible for reunification with family living in Canada.

As Jewish DPs began arriving in Canada, a more fundamental shift in immigration policy was in the offing. As the total flow of immigrants from Europe grew so large that a gradually increasing number of Jews could hardly be noticed, and as the newly independent State of Israel seemingly promised to absorb the bulk of remaining Jewish Displaced Persons, Canadian policy changed. In 1948, a new Immigration Act reaffirmed immigration as a national priority -- although it affirmed that there should be no fundamental change in the character of Canadian society as a result of immigration. Even so, immigration from Europe, including the arrival of Jews, was wide open.

Diversity of the Survivor Group

We may talk about Holocaust Survivors as a group, but those who arrived in Canada and other western receiving countries were also a diverse group. Their pre-War lives differed markedly one from the other -- some were religious, others not, some were urban and others rural, some were educated, others uneducated and unschooled. Not even the Holocaust bespoke a common experience for those who immigrated. They had no shared set of memories. Those who somehow emerged alive out of the concentration camps, the death camps and slave labour battalions, knew a different Holocaust than those who spent the war years hidden in the forests, those who fought with partisan groups, remained concealed by righteous gentiles, passed as non-Jews, or found temporary sanctuary in the Soviet Union.

In many other ways, they also demonstrated very few commonalities. They were young and old, spoke a polyphony of different languages, and reflected a multitude of previous nationalities. Some came with family. Others were the only survivors of their extended families or their entire communities. Some came to Canada under government or community sponsorships, some were reunited with a sponsoring family in their new country, and some eventually came as independent immigrants. Some were healthy in body, others less so. One can only guess at the variety of coping mechanisms these individuals exercised to keep their balance.

Survivor Settlement and Integration

If the Survivors' pre-War, wartime, post-War and immigrant arrival experiences differed one to the other, so did their initial years in their new home. The majority eventually found homes in larger urban centres, often moving into the same inner-city working-class immigrant-friendly neighbourhoods. However, their lived experiences provide a smorgasbord of integrative models.

And what were these lives? Again, the pattern is varied. In all my dealings with Holocaust Survivors, an admittedly random sample, I found some who simply set about rebuilding their lives. It was as if the Holocaust was part of a distant past and had little or nothing to do with their new lives. I found others for whom the Holocaust remained a constant presence, dogging their every step, invading their sleep, shaping their dreams and social relations, and giving them not a minute of true peace. There were those for whom the Holocaust became a cause, a foundation on which to organize activity, build friendships and lead fulfilling lives. Then there were those who denied the Holocaust a place in their lives. They buried memories inside, keeping secrets that were too frightening to be revealed or impossible to make others understand -- a taboo never to be mentioned. By contrast, there were those who could speak of little else.

After suffering so much pain and loss, it was no surprise that the process of Survivor integration or relations with the existing community was not always smooth, either at a personal or a collective level. Many Survivors have their own, often painful stories of those first few years in their new country.

There is one story of a new arrival in Canada who moved in with his older brother, a pre-War immigrant who was married and had a family. After the joy of reunion, relations between the brothers gradually became strained. Perhaps the two would never have been close, but divisions over wartime experience were too big a gulf to bridge. The household seemed to tiptoe around the Holocaust, not knowing whether to give it a place at the family table or banish it entirely, perhaps because they both wanted to know yet feared what they would hear. Then one night the subject of the Holocaust came up and, for the first time, the younger brother's wartime memories just began to pour out in a flood.

Perhaps the family was unable to absorb so much at one time. Perhaps they felt themselves overwhelmed by the horror of what they were hearing. It is hard to know. But at one point the older brother interrupted, seeking to add context of his own, "You know, we didn't have is too easy here either." He added, "There was rationing. There was no butter."

"No butter!" screamed the Holocaust Survivor. "No butter. What can you understand?" He stormed to his room, packed his bags and moved out. The two brothers did not speak again for years.

How many times this kind of confrontation was repeated in different families and in different ways across the community, we can only guess. Somewhat clearer was the approach of the organized Jewish community and more particularly of those assigned to assist in the integration of the new arrivals.

In some ways that response also resonated of the brothers' experience. For community workers, the first priority was to find homes, jobs and education for the new arrivals. But, there was an assumption that what was also needed was to get survivors beyond the Holocaust, to help put memory behind them, to assist them get on with their new lives, as if the Holocaust had never happened. And, what was the response to those DPs who were seen to wear the Holocaust on their sleeves like the yellow star that was so much a part of their past? They were candidates for counselling.

Perceptions about the Survivors

Too often a wall of silent ignorance divided Survivors, even from others in the Jewish community. Through the 1950s and into the early 1960s, Jews in Israel and the western Diaspora generally knew little about the Holocaust beyond the number "six million" and the name "Auschwitz." This historical vacuum reflected uneasiness with the Holocaust, a sense that Jews, in their alleged weakness, were somehow complicit in their own destruction.

This attitude found subtle expression in how the Holocaust was memorialized at the time. Yes, there was acknowledgement of what took place at Auschwitz, and "six million" assumed special meaning as a symbol of the Nazi crime. Many Jews sought comfort in commemorating Jewish resistance, as symbolized by the Warsaw ghetto uprising. But many remained haunted by the implications of Jewish impotence and subservience, and this negative view of the Holocaust spilled over into attitudes toward Survivors.

However, the image of the Holocaust and Survivors underwent a radical revision during the 1960s, both as a result of major events on the world stage and certain local events. In May 1960, the State of Israel announced the apprehension of Holocaust mastermind, Adolph Eichmann. His trial in Israel for "crimes against humanity" and under Israeli law for "crimes against the Jewish people" exposed Jews and non-Jews alike to the larger historical reality of the Holocaust, as no other event had done before. The trial was a critical moment in turning the Holocaust from a private Jewish agony into part of the western historical legacy _ an event of monumental proportions destined to plague historians, moral philosophers and the conscience of mankind.

After the Eichmann trial, thoughtful people could no longer dismiss the Holocaust as a momentary excess of a few extremists run amok; nor could they decry the silent acquiescence of the victims in their own destruction. The Holocaust was now documented as the centrepiece of a political and racial ideology with deep historical roots, an ideology that commanded the loyalty of millions. There was recognition at last that the Holocaust was a series of events from which most Jews had no escape, and against which they could offer no effective resistance. Indeed, resistance itself was redefined. It was not just the partisans. It also included dignity in the face of persecution, affirmation of life in the face of certain death and determination to hold the perpetrators accountable in the face of seeming world indifference. Out of the Eichmann trial came not only a new understanding of the horrible events of the Holocaust, but a recasting of the remnants of the Holocaust horror. They were no longer DPs, they were Holocaust Survivors.

Today, the realization that Survivors are aging has also spurred efforts to gather and record their life experiences. These efforts, designed to preserve memory across generations, have also given many Survivors a renewed sense that their life stories -- in all their diversity -- are worth preserving. And what of their legacy? I leave that for others to judge. But, certainly part of the Survivor legacy, must be the recognition that the children of Survivors -- the second generation - now constitute the backbone of organized Jewish life everywhere. This, in the end, may emerge as the most impressive and lasting monument to those remarkable men and women who somehow survived the Nazi Holocaust and its aftermath.

Understanding the Survivors

Challenges that May Elicit Difficult Memories

Sandi Pelly, B.A.

In order to understand Survivors, one must accept that a true understanding is impossible. We cannot fathom the horrors and losses that Survivors have endured but we can and are obligated to listen and support them in the telling. We can try to understand what they have experienced and how they have internalized those experiences and coped in the years that followed the War. As each story is unique and each person is different, there are no comprehensive sets of rules or guidelines to follow when caring for aging Survivors. Yet certain vulnerabilities and attitudes shared by many Survivors may help sensitize those who care for them in later life.

"Best practice" means being aware of as many potential concerns as possible in order to knowingly and sensitively respond to an individual. In order to listen well, the following should be kept in mind:

Vulnerability to loss and illness: Holocaust Survivors may be particularly vulnerable to experiences that are often part of the aging process, such as loss, separation, illness or institutionalization. Because there was no opportunity to grieve or mourn during these catastrophic years, an experience of extreme stress may elicit volcanic feelings of the past and produce complicated problems.

Need to "bear witness": Many Holocaust Survivors have a strong need to "bear witness." As eyewitnesses to an unbelievable chapter in human history, Survivors want to make sure that the Holocaust is never forgotten, and that future generations know about it in ways that are not distorted. Many are frustrated when the media commercialize, popularize, trivialize or inappropriately universalize the Holocaust. You may encounter Survivors who feel that "bearing witness" is threatening or intrusive. As part of their coping mechanisms, many Survivors have constructed the narrative of their War Years in a manner that generates the least pain. They may have chosen to keep silent, or just share aspects of their experiences, and have no desire to share their story now. In as much as we should honour a Survivor's need to bear witness and document personal testimonials, we should also honour a Survivor's need to avoid doing so. In both instances, individuals may change their minds as they age, and regardless of directive, we should be supportive.

Absence of kin: Aging Survivors without kin - family and close friends - may be a group at risk and thus need increased community supports. These individuals are truly alone in the world, since their contemporary Survivor friends who constituted their "new" families after the War have either passed on or also coping with aging and loss.

Environmental Factors and Potential Triggers

Paula David, MSW, Coordinator, Holocaust Resource Project, Baycrest Centre

Specific circumstances have the potential to trigger painful memories for Survivors of the Holocaust. A trigger is something that may bring back difficult memories for a Survivor. (see the following pages for a detailed list of these potential triggers.) Reminders of the trauma of the Holocaust are always present - different ones for different people. When a Survivor is ill, cognitively or physically impaired, or just feeling vulnerable, particular events, objects or comments may become triggers. Many normal day-to-day activities or situations may provoke an adverse physical, emotional or behavioral reaction. This is especially true within the institutional environment of hospitals and long-term care facilities.

It is important to remember that what may be a trigger for one individual may not cause another any difficulty at all. All frail Survivors may respond to any number of triggers with a specific memory or a flooding of memories, but the cognitively impaired patient may actually feel as though she is reliving the memory. Aging, sickness and impairment may make some Survivors susceptible to triggers that were not an issue when they were younger. Caregivers should be aware of the more common triggers, and appreciate that even common triggers recall unique and different memories.

Advancing age and ill health means more and more Holocaust Survivors are having contact with health care workers in hospitals, institutions for the aged, and in the community. Aging itself is a difficult process for Survivors, and some Survivors are reluctant and even afraid to ask for help. Basic trust has been destroyed and many are suspicious and cynical. There is a need to understand how to provide the exceptional care to this extraordinary and heterogeneous group.

The Triggers and Response Tips in the following pages will be referred to throughout the Manual. At all times staff and family members should consider the individual needs of the person they are caring for as well using personalized common sense, encouragement and caring.

Click here.

Communication with Survivors

The Jews of Eastern Europe generally spoke more than one language. For many years, Europe's borders were changeable, and citizens learned the languages of neighbouring countries to accommodate these changes. Even before the War, Anti-Semitism had been rearing its ugly head in different countries, at different times, and with different levels of harshness. In many countries, Jews were restricted in the type of work or education they could obtain, and so were forced to travel both for business and study. Often Jews had to leave a country in order to find safer havens, and so it was not uncommon that each family would have acquired more than one country's language.

Jews typically learned and spoke the native language of the country in which they were born. At the same time, many Jewish families spoke Yiddish in their homes; a language that is derived from German and rich in its ability to express both sorrow and joy. Jews pray in Hebrew, an ancient language that evolved into a modern expressive one with the growth of Israel. Therefore the majority of Survivors, in the course of their pre- and post-War lives -- and also their deportations, relocations and emigration - speak a range of languages.

When older adults become ill, lonely or cognitively impaired, they may not be as comfortable expressing themselves in the languages that were most recently acquired. If they are in pain, they may be comforted by hearing the language of their youth, which reminds them of times when they were healthier and happier. Obviously family members and health care providers are not expected to be fluent in a range of languages, but the occasional word, a simple question or a reassuring phrase spoken in the Survivor's language, may make a world of difference to an older client.

Here are some common terms and expressions that caregivers should be familiar with.
These Language Charts include words related to health, well-being and family, and may help caregivers communicate with and comfort Survivors:

Don't worry about your pronunciation, it is the effort and the caring behind it that will have a positive impact on your patient.

CARING FOR AGING HOLOCAUST SURVIVORS

Family Members as Caregivers

Providing Care

Providing Care for a Spouse

Very often, following liberation, Survivors married other Survivors. Family life for Survivors after the war took on many different meanings.

Often couples came together in efforts to survive and not because of love. Love was often not the impetus for couples to marry. Instead goals such as mutual dependency, protectiveness and an ability to build a new life fuelled many of these unions. In other instances there are remarkable stories of young couples wrenched apart, enduring separate traumas in separate locales, and remarkably being re-united following liberation.

In either case, these young families tackled post-War challenges with a resiliency that was unprecedented. They coped with starting over again in new countries, learning new language and customs and finding new jobs - all in the wake of very recent comprehensive and traumatic losses. These couples succeeded by forming "Survivor partnerships," each with its own unique identity, qualities and coping mechanisms. Their commonality was that they worked and functioned as a dyad.

Now these Survivors are finding that age and illness present very real threats to that dyad. Given that one person of a couple may be ill and need help, the logical outcome in most Survivor families is that the healthier spouse will provide care. Family members and professionals should understand that these are often symbiotic (mutually rewarding) relationships in which couples generally coped quite well - so long both partners were healthy.

It may be difficult for spouses who are caregivers to trust "outside" help or even to ask for it. While one partner may be ill, both are aging and coping with change. Spouses who are caregivers have the right to be informed about all aspects of their partners' medical and daily care, including diagnoses (the nature of an illness) and prognoses (how the illness is expected to proceed.) They should also be encouraged to become active partners in all aspects of care.

To ensure this, spouses must share as much information as they have about their partners. They must also recognize that love and commitment to an ill husband or wife are their own unique and important contribution to quality care.

At the same time, Survivors themselves must be prepared to accept support from family and appropriate health care providers. Aging and its related illnesses are new experiences and help is available.

Providing Care to a Survivor Parent

For children of Survivors, caring for an aging parent brings with it a mix of emotions. Their parents experienced many traumas, and now their children want to protect them and provide care.

The burden of care giving often rests with adult children because Survivors have no other relatives. Also, most Survivors have no experience with aging because they were robbed of the opportunity to watch their own parents grow old and never had the privilege of watching extended family members experience aging as a natural life process. If no one in the family know what to expect, they had no practical examples of elder care.

Aging is part of the natural life process, and its conclusion is death. But for many Survivors, who faced their own mortality prematurely during the Holocaust yet managed to survive, death is still considered as a personal defeat. In order to survive, they beat all the odds, and this tenacity that served them so well in their youth may complicate their aging.

In many instances, parents couldn't teach children about death because they themselves had never learned how to handle death or how to grieve normally for their lost family members. In their experience, a death in the family was related to mass murder and multiple traumatic losses. It is often the children of Survivors who must help their parents learn to be old (and in many cases, teach them how to enjoy life.)

At the same time, these children must face their parents' natural mortality. Compounding this anxiety is a paradoxical familiarity with the concept of death. Many Survivor children were raised in a unique environment where genocide was part of the fabric of family life. It is especially difficult for these children to deal with the "normal" realities of aging parents.

Mrs. L.'s Story

Just before the Nazis invaded Poland and closed the borders, Mr. and Mrs. L. managed to escape to Siberia with their two young daughters. Mrs. L. had come from a wealthy family and always enjoyed having servants to help her with her household duties. She was a frail, delicate woman who relied on her strong and handsome husband to keep them safe and make difficult decisions.

Within two months in the cold harsh climate of Siberia, Mr. L. died of pneumonia. Mrs. L. was left with an infant and young daughter. In order to feed them, she trudged several miles each way to work in a bakery. Her daily pay was a loaf of bread and a few coins to purchase some root vegetables when they were available. Her eight-year-old daughter took care of the baby for the 12 hours she was away each day. But eventually, unable to live under harsh conditions of cold and hunger, the infant died in her sleep. Mrs. L. and her surviving daughter walked for two weeks, carrying the dead child, until they could find a rabbi to say the prayers and bury the baby.

Mrs. L. and her older daughter managed to survive, and after the War, finding no other living relatives, they came to Canada. Mother and daughter were inseparable. There Mrs. L. married another Survivor from her hometown.

All she wanted was for her daughter to have a home, a father and be like the other children. She was convinced that a nice house, a good school, and lots of healthy food would ensure her child's happiness and security. Mrs. L. worked as a seamstress in a factory by day, studied English by night. She worked hard in order to give her daughter the finest things, the best education - but her daughter never seemed happy like all the other teenagers. In fact, after the War was over, Mrs. L. and Her daughter were never close again.

Grandchildren

Many Survivors who have grandchildren say that "This, these children, are the reason why I survived." They see this third generation as a symbol of hope for the future, and their relationships give substance to memories and the family legacy.

Grandchildren can play a special role in caring for their aging Survivor grandparent(s). Such relationships are generally not complicated by past authority conflicts and painful memories. Warm childhood memories of the grandparents may contribute to bonds of affection. For these reasons, regardless of their age, grandchildren can often approach "care giving" with energy and optimism that greatly exceed what their own parents are able to supply.

It is a different, enriching and hopeful relationship, and one that has the potential to bring great comfort to older Survivors in the midst of other losses. The opportunity for a grandchild to contribute to a grandparent's life can be a mutually beneficial learning experience, which creates cherished memories.

Grandchildren have opportunities for closeness to these Survivors, closeness which may not have been possible for their own parents. Adult children of Survivors should be aware of these potential intergenerational bonds and wherever possible, help them to flourish.

Educating Personal Care Workers about caring for Elderly Survivors

Accepting help from outsiders can be a very difficult decision for Survivors and their adult children. There are issues of trust, including fears about having a stranger in the home, that some families find hard to overcome. Often, the perception is that a paid caregiver can never be good enough, and the subsequent guilt associated with that assumption is sometimes overwhelming. For adult children who live in a different city or country than their parents, the issues often multiply. Quality assurance, maintaining the exchange of accurate information and the practical costs involved are some of the barriers to peace of mind.

Often the cost of hiring a private care worker may be prohibitive for elderly Survivors, or else they may not be willing to spend their hard-earned money on outside help. In order to sustain, afford and/or ensure quality care, families must work together and often quite creatively.

In some communities subsidies may be available for Survivors who require personal caregivers. Adult siblings may have to pool their resources. Sometimes adult children of Survivors misrepresent the actual cost to their parents, "topping up" the amount given to the private caregiver. In general, in order to sustain trust through difficult times, it is best to be as forthright as possible.

Families are not the only ones who face challenges in caring for elderly Survivors. Personal care workers and homemakers are also affected by their clients' history. Such caregivers must understand the unique and traumatic events which shaped these older people and which may impact on their care.

Adult children of Survivors can provide private caregivers with some of the information contained in this manual. They can also share personal information about an elderly person in an effort to increase the caregiver's understanding, appreciation and sympathy for this person whom they are meeting at the end of a long and complex life. Here are some tips on how to educate a private caregiver who is looking after an elderly Survivor:

If the person does not speak the same language as your parent, make sure that they understand key terms for the Survivor. Certain words have very specific meanings.

Explain why food may be particularly important to your parent, and describe the type of cooking that will be most familiar and comforting.

Discuss your parents' history so that the caregiver is more aware and prepared when something comes up in conversation. Let the caregiver know how your parent feels about sharing his or her war-time experiences. Explain that some Survivors want others to know and will tell everyone about their past, while some prefer to say nothing.

Clearly identify your parents' triggers' or particular sensitivities. If disrobing brings back memories of their clothing being removed at Auschwitz, ask the caregiver to explain in a soft voice that it is time to bathe, and that they should avoid rushing the Survivor in any way. To help you identify specific triggers, refer to our section on *Challenges that May Elicit Difficult Memories*.

To the best of your ability, inform the caregiver about what traumas your parent experienced before, during and after the War, and what their reactions might be today. Take time to regularly communicate with the caregiver. This effort will pay off in better quality care for your parent, and peace of mind for you.

If the caregiver is from an agency, explain to the agency the importance of consistency. A Survivor may have trust issues, and it's vital that they have person with them from day to day.

Refer to the section: Caring for the Caregivers

Planning for changes in abilities or functioning

The normal changes associated with aging were discussed earlier in Part 1. Physical and cognitive changes are inevitable as people age and the best way to cope with changes is to be as prepared as possible. When a Survivor parent has a progressive physical or cognitive disease, here are some ways you can prepare for changes that may occur over time.

Be aware of your parents' wishes (for example, how they feel about "do not resuscitate" directives), especially if their health deteriorates significantly. Don't be afraid to have conversations about what medical interventions they do or don't want. Your opinions may be very different, so it's important that you ask them. Having this information will make it so much easier on you at the end of their lives. Should the Survivor parent refuse to discuss their wishes about end-of-life care, you might want to consult with a member of his or her health care team (a family physician or member of the hospital/nursing home staff). Choose someone you feel comfortable with and explain the circumstances.

Give your parent permission to talk about death. Even though the Survivor may have made it clear your entire life that this subject is taboo, you should take a risk and initiate a discussion about their wishes near the end of their life. Remember -- they have experienced so many deaths themselves, and may not have felt a sense of closure. For these reasons, it may be especially important in their minds that you grieve properly for them after they die. They may have ideas about where they want to be buried, what they want on their headstone and what kind of funeral service they want. If you don't ask, you will never know. Of course, if they don't want to talk, let it go and respect that this is an issue of monumental proportions for anyone, especially a Survivor.

If your parent is losing cognitive abilities, this may exacerbate their traumatic memories. Ensure that anyone providing care understands these implications. It is important to arrange and coordinate appointments to be as efficient as possible in order to minimize stress.

Be flexible and willing to change your care giving plan. You may need to develop different tactics for different stages of the Survivor's illness and deterioration.

Talk to other "second generation" children who are in similar circumstances. They will understand the differences in caring for a Survivor parent and will be able to listen and understand what you are going through. Having someone to share it with will make the journey a little easier.

Encourage your parent to talk with friends who are Survivors. These people share a common bond, and Survivors may find it easier to share things with these contemporaries than with family members, whom they may still wish to protect.

Learn as much as you can about the Survivor's diagnosis and prognosis, so you'll be prepared for changes and decisions to come.

Alzheimer Disease

Alzheimer Disease (AD) is the most common form of dementia affecting elderly people. The symptoms of AD may include a loss of memory, judgment and reasoning, changes in mood and behaviour and the inability to perform familiar tasks. AD is not a normal part of aging. Family members should understand that AD is a degenerative disease with no known cause or cure at the present time. However, new so-called cognitive-enhancing medications can delay progression of the disease. .

Research shows that several changes occur in the brains of people with AD:

- the brain cells shrink or disappear and are replaced by dense, irregularly-shaped spots, or "plaques"
- thread-like tangles appear within existing brain cells; these tangles eventually destroy healthy brain cells
- a person with AD has less brain tissue than someone without the disease, and this shrinkage will continue over time, affecting how the brain functions

Most cities have an Alzheimer Society or similar service. These agencies are an excellent resource and have comprehensive educational programs. When discussing your relative with professionals, make sure they are aware that the person is a Survivor.

The Three Stages of Alzheimer Disease

Tips: Caring for Survivor Parent(s) Living in the Community

Learn to separate the care you provide to two parents, especially if one has greater needs than the other. Ensure that you don't bring the stronger parent down by placing too many caring demands on him or her.

Look after yourself. A "burned-out" caregiver is of no use to anyone. Children of immigrants are used to taking care of everything, but when a parent needs physical care giving, the burden is greater, so give yourself a break! Realize you have limitations and get help if you need it. Read the information on caregiver burnout and practice the tips provided.

Try to appreciate that you are doing your best. Don't become trapped into feeling guilty for "not doing enough." You are doing what you can do, and must also live your life.

Get help from others. Most families do not fully use the community services available to them. They may be unaware of services or confused by eligibility criteria and paperwork. Survivors may resist having "strangers" in their homes, and families should expect to invest extra supportive time when a new caregiver arrives on the scene.

Anxiety about the expense of hiring outside caregivers may be another burden. Don't underestimate the value of having respite (for yourself, your own spouse and children), and also the advantages of consistent care for your loved one. Know that help is available, and find out exactly what such services can do for you. In some communities, respite volunteers may be able to provide companionship if your parent is willing to receive this help.

Keep organized. Maintain copies of your parent's health and medication records so you can provide this information when necessary. Part of this package should include a brief (half page) personal biography of your parent, underlining his or her Holocaust experience, as well as post-War accomplishments. This reminds outside caregivers that each Survivor is a strong and resilient person with a history of sorrows, joys, talents and achievements.

Institutional Care

Decision to Move to an Institution

Sometimes, family caregivers continue caring for an elderly Survivor at home until they themselves are exhausted, both physically and emotionally. Deciding that you can no longer care for your relative is one of the most difficult decisions you will have to make.

Decisions about placement in a long-term care setting are often made in reaction to a crisis, such as discharge from an acute-care hospital. It's much better to start thinking about this possibility and exploring your options before a crisis occurs.

As a child of Survivors, the topic may seem monumental and unmentionable. Often there is a transmission of the parent's early trauma during the Holocaust to his or her adult children. In such cases, the normal "mixed feelings" often experienced by children without a Survivor background, may add to feelings of guilt and defeat.

Some adult children of Survivors have ambivalent and unresolved feelings towards their parents, or towards their parents' experiences in the Holocaust. They feel especially threatened or vulnerable when confronted by the idea of losing an elderly mother or father.

For Survivor families, the thought of placing their family member into a long-term care facility is synonymous with defeat. The children of Survivors tend to see their parents as people who overcame inconceivable obstacles, and it may be difficult to reconcile this long-held image with a mother or father who is growing more and more frail and dependent. There is also a real concern that relocating a Survivor to an unfamiliar environment may trigger many painful memories of the Holocaust.

But eventually, families have to look at their individual situation realistically. If providing care at home has become too exhausting or impossible, or if an elderly Survivor clearly requires professional, round-the-clock medical care and supervision, there may be no other choice. It is important that families explore and discuss these issues so those involved in caring for the Holocaust Survivor fully understand the family's feelings and concerns.

Red Flags for Nursing Home Placement

Burdensome incontinence: Strenuous effort is required to prevent skin breakdown.

Too much heavy lifting: The caregiver is unable to lift and transfer the person safely, despite having received training in special techniques and the use of assistive devices.

Caregiver is sleep-deprived: The caregiver's sleep is disturbed on a nightly basis and relief help is not available frequently enough or at all.

Caregiver becomes ill or injured: The caregiver tries to go on providing care while neglecting an illness that requires medical attention or extended rest from care giving.

Other stresses impinging on the care: The caregiver is going through a divorce, coping with another illness or a death in the family, or facing problems with finances, employment, or dependent children.

From Wendy Lustbader and Nancy R. Hooyman, Taking Care of Aging Family Members New York: The Free Press, 1994.

How to Raise the Topic with the Survivor

Raising the subject of long-term care may be uncomfortable, even in families with a history of open communication and where elderly parents are realistic about their needs. Other families find it almost impossible to consider the concept of institutional care, and will understandably, have great difficulty discussing it. This is an emotional and complex subject, where rational discussion may go unheard. If you are concerned about your parents' response to placement, perhaps a trusted physician, relative or friend would agree to cautiously initiate the discussion. Survivors, who are often intent on protecting their children, may respond differently and more positively to a trusted outsider. Where possible, allowing time to consider and reconsider the options is helpful.

Issue of Relocation for Survivors

Whenever possible, advance planning for placement is preferable. This allows the older person to participate in the decision-making, weigh in on various choices, and have some time to "prepare'." During the War Jews were often wrenched from their homes and families with no prior warning, and the always ended up in infinitely worse circumstances.

Allowing the Survivor to become familiar with the destination, the plan and the process will alleviate some anxiety. Where possible, the family should select a facility with an awareness of caring for Survivors. The environment should provide familiar foods and relevant Jewish programming. Familiar photos and personal items should be in place when the individual arrives.

Staff Sensitivity

Staff need to understand that feelings of "giving up" may be more pronounced for Survivors. They must be helped to appreciate why the decision to move into long term care can be so emotionally difficult for Survivors and their families. For example, they should be informed that the Survivor's immediate family is his or her only family (if that is indeed the case). Encouraging continuity in family connections and recognizing the client's unique needs are particularly critical to ease the adjustment.

The Survivor family may be more protective than families of other clients, and may want to be more involved in planning care. Staff should understand the reason for this need and support it. Remaining involved in the care planning will help children of Survivors feel better about the decision to place their parent. Staff should see this as a help rather than hindrance. In the end, it's up to families to explain their unique circumstances and family history to those providing care.

The "Door Story"

It's important that staff in long-term care facilities understand and appreciate the people under their care. Staff who see their patients as people first form stronger bonds and ultimately can provide more compassionate care.

An easy, inexpensive way to for families to encourage this attitude is to create a "Door Story." This is a simple project, one which grandchildren can take part in.

Take a piece of standard size Bristol board, print your parent's full name in large block lettering. Then highlight some of her major life events and accomplishments in brief point form. Include a photograph of her in younger, healthier days, and maybe a family group photo. Hang this board on the door to her room, so that anyone walking by will be reminded that she had a full and interesting life, that she may have endured trauma, but that she also achieved successes. Most of all, the "Door Story" serves to remind staff that this frail, elderly person has a family that loves her. The "Door Story" may also be a source of pride to an older person, and its location on the door can help orient her to the new environment.

Other tips to assist the staff in providing the best care include:

It is important for family members to know that their loved one is safe. Staff may need to provide extra reassurance, particularly in the first days and weeks after admission. If family members are anxious, they should explain how difficult and threatening separation feels to them, and perhaps explain why

Families should take time to educate the nurses, doctors and other care providers about an elderly parent and his/her circumstances. This will go a long way towards ensuring better, more sensitive care.

Caring for me: Survivor perspectives

Survivors in long term care facilities have the same needs as all older adults: they need quality care, respect and some recognition of who they were, including what they may have endured and how much they have achieved despite a history of trauma. They certainly deserve an extra amount of compassion during the last chapter of their lives.

Caring for Parents in a Long-Term Care Facility

Ruth Goodman, MSW, Baycrest Centre

When your parents are Survivors, and if their frailty and dependencies increase, you may be profoundly affected by the ongoing struggles and determination they exhibit. As a child of Survivors, you may be dealing with an entanglement of losses, witnessing the gradual loss of physical and cognitive capacity of your parents. Diminished cognitive capacity is a profound loss, as shared memories, stories, and anecdotes are an integral part of all relationships. If these become fragmented, new ways of being together are needed.

The loss of independence that usually precedes and follows admission to long-term care can be a devastating blow. The decision to place a parent is difficult for any family, but for children of Survivors these difficulties are especially profound and complex. Often adult children make commitments to themselves and/or their parents which, when faced by the realities of aging and illness, they find themselves unable to keep.

Admission to a long-term care facility should not be seen as a failure. When it is the only option, you should know you are supporting your parent(s) to the best of your ability. That is all any child can do.

Dealing with a parent's frailty and incapacity may trigger adult children to recall their parents' experiences during War years. Their resilience, fortitude, ingenuity, anguish and their losses are all remembered. Layered on top of this are the struggles, achievements, and losses of the post-War years. As a child of Survivors, you may be dealing with multiple layers of loss, and depending on the nature of your adult relationship with your parent, you may be able to find ways of understanding and responding that support the integration of all these realities.

Providing intimate physical care to one's parent offers opportunities for healing and closeness that can be deeply felt by both. As the losses of aging increase, emotional processes are altered. One's sense of one's body changes, and Survivors are often not able to express those feelings. Physical closeness with your parent can be a healing experience. There is comfort and satisfaction that you are needed and loved, that you are involved in the daily fabric of life. Mixed with the emotional pain of seeing our parents' abilities fade is the comfort of knowing that you have shared those moments, that you were there for them, and that you have provided assistance.

Children understand their parents' need for and reaction to care different ways. For some, instances of resisting care may remind the children of the degradation and pain of the concentration camps. For others, issues around food and intake hold great symbolic weight. Rational thought is often insufficient in trying to problem-solve these situations. The spectre of starvation, malnutrition, withholding and deprivation are some of the strong emotional reactions you may be faced with as your parents' capacities diminish.

With admission to long-term care, you may feel overwhelmed by more recent losses, as the losses of the past recede and others are felt more acutely. After all that your parents have already endured, these current losses seem unfair. Because your parents are dependent and vulnerable, it is understandable that you want them to receive the respect, gentleness and support that they deserve.

To help staff provide the most sensitive care, you can share your parents' family history and stories. Try to capture, validate and remember the core of their personhood, their life-long struggles and their accomplishments. As much as possible, become part of the care team. Work closely with staff, advocate for your parents, and provide as much physical and emotional support as you are able. Remember the importance of caring for yourself during this potentially draining time.

Suggestions for Visiting Parents in Long-term Care Facilities

It is never easy to visit a relative in a hospital or long-term care facility, where you are inevitably reminded of better and healthier times. In many cases, families can enjoy reminiscing during such visits. But such healing conversations may not be possible among many Survivors and their families. This is especially true when dementia is a factor. Visits may be even more painful, as past and present get confused and the resultant guilt and pain become exacerbated.

Here are some suggestions that might make visiting more pleasurable for all family members.

Some Activities to Enhance Your Visits

- Go for a walk of the floor - visit the gift shop, or go outdoors if possible.
- Do some gentle stretching or range of motion exercises. Consult with the physiotherapist/occupational therapist for instruction.
- Attend recreation programs together.
- Listen to tape-recorded music brought from home. Add a variation by playing "Name that Tune".
- Sing songs together, even if they are a little off-key.
- Bring in a pet to visit, in accordance with the facility's policy.
- Children add joy to a visit. Ask them to bring some of their favourite toys to share with your relative.
- Read a book, magazine, short story out loud. Talking books (books recorded on audio tapes) are also an option.
- Bring in a joke book and have a laugh.
- Bring in books of photographs, which show various countries, familiar personalities or outdoor scenes.
- Bring in family photo albums and reminisce.
- Read "Dear Abby" newspaper columns and discuss what advice you might give.
- Explore the day's newspaper.
- A new manicure is easy to do; for mothers or grandmothers, a fresh coat of nail polish might be appreciated.
- Test out new perfumes and aftershaves.
- Pamper your relative's hands by massaging them.
- Try a new hairstyle with hair spray, curlers and other accessories brought from home.
- Try doing an arts and craft project together - knitting, crocheting, painting etc.
- Bring in fresh flowers and make a floral arrangement.
- Care for plants, or plant an indoor bulb and some seeds and watch them grow.
- Sand wood blocks and paint them.
- Play a board game or a game of cards.
- Attend an outing together - either one planned by the facility or just with your relative. Discuss plans with the staff - for example, a trip to a restaurant for lunch, a few hours at the mall or an outing to the park during warm weather.

Decision to Move into a Seniors' Residence

Shawn Fremeth, MSW, Elaine Kohn, MSW, Heather Lisner-Kerbel, MSW, Frances Cossever, MSW, Barbara Biel, MSW, Baycrest Centre

Moving into a community-based seniors' residence, such as a supportive housing complex, often poses numerous challenges for older adults and their children. For an elderly Holocaust Survivor, the nuances of such challenges may take on an added complexity and intensity. Although there are differences between community-based settings and long-term care facilities, the fact remains that both are communal environments that provide varying degrees of "institutional" support and structure.

Institutional norms that exist to ensure the proper running of a community setting can be disturbing to a Holocaust Survivor. Medical staff, mealtime schedules and other imposed organizational routines set up for community efficiency may be stressful and disturbing to Survivors. Factors associated with the decision-making process, such as choice, timing and motive often have a tremendous impact on making the transition to a new living arrangement.

To better understand the challenges that your parent may face in adjusting to a seniors' residence, it is crucial for you to give staff a clear sense of how the decision to move came to be made. While your parent may not require nursing home level care, a decline in physical functioning and an increase in social isolation often precipitate a move to a supportive housing complex. While there may be an intellectual recognition of the need for more support, the emotional sequalae associated with this decision may be varied and layered.

For Survivors and their children, the decision to move to a supportive housing environment encompasses numerous issues. The degree of perceived control over one's future is of tremendous importance to any older adult. This fundamental need may take on unique symbolic value for Survivors given their lack of choice and the trauma they faced early in life.

Your parent may feel an overwhelming sense of loss of control, ranging from the tangible, (i.e. giving up possessions, what to bring and leave behind) to intangible losses (i.e. feelings of weakness and not being able to manage one's life independently). The importance of maintaining independence - defined literally as complete self-sufficiency - also takes on unique meaning. Such independence meant the difference between life and death during the War, and later on, success and failure after the War. Independence was the bedrock upon which Survivors rebuilt their lives, and to acknowledge a decline in this area -- to themselves and also to the rest of the world -- may be a source of tremendous insecurity. The Holocaust Survivor may feel it is necessary and appropriate to befriend and please staff by offering gifts in order to get what they need/want in the supportive housing environment. Such a strategy was often key to survival during the War.

Case Example: Mrs. P.

Mrs. P. survived Auschwitz concentration camp where she witnessed the deaths of her two brothers and three sisters. She sustained many losses throughout her life. For 45 years, she lived in the community with her husband, also a Holocaust Survivor, until she was forced to live alone and cope with the difficulties inherent in widowhood.

Mrs. P.'s three adult children were married with families of their own. Two of the children lived out of town, and one daughter lived nearby with her family. Consequently, this daughter became largely responsible for providing emotional and instrumental support to her mother. After 10 years of being on her own, Mrs. P.'s physical health began to decline and impact on her ability to live independently. After sustaining injuries related to a fall and a decline in ability to manage daily tasks (e.g. housecleaning, meal preparation), Mrs. P. was forced to seriously consider the need to move into an environment that would provide more support. Mrs. P. was also becoming increasingly isolated as many of her friends had passed away, and she found it difficult to travel to the community centre she used to visit regularly. As a result, she was starting to feel depressed.

Dependent on Rifka, her only child who lived nearby, Mrs. P. called her daughter and asked "what now?" Both Mrs. P. and Rifka felt uncertain about the future and didn't know what lay ahead. Rifka was becoming increasingly worn out from her care giving responsibilities, and her stress level was rising. Although she knew the situation was not sustainable, she felt tremendous guilt for even considering that her mother needed to leave home. How could she uproot her mother at this stage of her life?

Rifka was angry at times that her siblings were so far removed from the situation. Mrs. P.'s two other children felt guilty they couldn't offer more support to their mother and sister. They really weren't sure what would be best for their mother. Mrs. P. seemed to recognize many of the benefits of moving to a supportive housing complex, but she clearly felt ambivalent about making such a move. Mrs. P. wondered how she could leave an environment that held so many wonderful memories for her. She was reluctant to travel down a new and unfamiliar path.

Discussion of Issues raised in case

Leaving a familiar environment creates a great deal of stress for Survivors, since it reminds them of the time they were forced from their communities. The trials and tribulations that followed such "leavings" are unimaginable, and their impact is often felt many decades later. While Mrs. P. knew she needed greater assistance because of her increasing physical frailties and recognized that her increased isolation was causing her to feel depressed, she was ambivalent about leaving that which was familiar to her and to journey into the unknown. It is important for her children to recognize this struggle while at the same time, to support her in deciding to live in an environment that would be the best given her situation.

Some family members see this type of move as a failure to "protect" and support their loved one. An additional factor that may create further complexity stems from the geographical location/proximity of adult children. Children of Survivors often feel a tremendous sense of responsibility for their parents.

In Mrs. P.'s case, the "burden" of overseeing activities of daily living, (ie. financial and medical responsibilities, shopping, transportation, meals) fell on Rifka. For the children who do not live locally, the dominant feeling described is guilt related to their inability to provide instrumental support. This imbalance often causes feelings between siblings to become strained. Such issues may need to be addressed by exploring how each family member perceives the move, what it means to them, and what each sibling can contribute in the best interest of their mother.

In the ideal situation, there is congruence between the Survivor and all family members regarding the decision to be made. This, however, is not always the case. It must be emphasized that when an older adult is capable of making decisions regarding their living arrangements, they must be empowered to do so, regardless of what other parties believe. Although some may perceive a decision to be foolish or unwise, the right of a competent individual to make his or her own choice must be protected and respected.

The losses generally experienced as a natural part of the aging process may be magnified in a setting where a group of elderly people live. Within such an environment there is a continuum of ability/disability among residents, and the physical and cognitive losses that Survivors see in others may be striking. They may be forced to recognize such losses in themselves or speculate on what the future may hold. This may arouse feelings of anxiety and fear of the future.

It must be emphasized again that those who survived the Holocaust did so in most cases because they were well and able. They did, in a very real sense, outwit death. Moving into an environment where disease and death are more visible may stir up a wide range of emotions that should be addressed by family members with the help of health care professionals when needed. Family members should not see this move as an opportunity to offer parents less support. More than ever, parents need to know that their family will visit, will remain interested and involved, and will be there for them.

Tips for Dealing with Stress and Tension

Courtesy of Heart and Stroke Foundation and Canadian Mental Health Association, Coping with Stress Toronto, 1997.

Stress and tension are normal reactions to events that threaten us. Such threats can come from accidents, financial troubles and problems on the job or with family. The way we deal with these pressures has a lot to do with our mental, emotional and physical health. For more information about coping with the impact of caring for aging survivors, please refer to Part 3 of this manual. The following are suggestions to help you manage the stress in your life.

Recognize your symptoms of stress.

- Look at your lifestyle and see what can be changed - in your work situation, your family situation, or your schedule.
- Use relaxation techniques - yoga, meditation, deep breathing or massage.
- Exercise - physical activity is one of the most effective stress remedies around!
- Time management - do essential tasks and prioritize the others. Consider those who may be affected by your decisions, such as family and friends. Use a checklist so you will receive satisfaction as you check off each job as it is done.
- Watch your diet - Alcohol, caffeine, sugar, fats and tobacco all put a strain on your body's ability to cope with stress. A diet with a balance of fruits, vegetables, whole grains and foods high in protein but low in fat will help create optimum health.
- Get enough rest and sleep.
- Talk with others. Talk with friends, professional counselors, support groups or relatives about what is bothering you.
- Help other. Volunteer work can be an effective and satisfying stress reducer.
- Get away for awhile. Read a book, watch a movie, play a game, listen to music or go on vacation. Leave yourself some time that's just for you.
- Work off your anger. Get physically active, dig in the garden, start a project, get your spring cleaning done.
- Give in occasionally. Avoid quarrels whenever possible.
- Tackle one thing at a time. Don't try to do too much at once.
- Don't try to be perfect.
- Ease up on criticism of others.
- Don't be too competitive.
- Make the first move to be friendly.
- Have some fun!! Laugh and be with people you enjoy!

Lessons Learned for Children of Survivors

Paula David, MSW, Coordinator, Holocaust Resource Project, Baycrest Centre

The following are some practical tips from adult children who are caring for their Survivor parents:

Know who you are in every part of your life. Know what you can live with and what will make you feel guilty so you don't have any regrets. Know how much time you can commit.

Expect less of yourself, and do as much as you reasonably can.

You can't make your parent better, so do what you can and know what decisions you can live with and what decisions you can't control.

Be organized ... be patient ... do the best you can.

Have the strength to deal with your parent and the awareness that she has to take care of herself as much as she is able to.

Take care of yourself.

Don't see asking for help as a failure.

Recognize that the Holocaust has had an impact on your family ... even if you are not clear on what it is. Then recognize that your family and your parents are much more than just "the Holocaust." Focus on creating quality time with your parent, even while that definition may be changing. Make the most of the time you have.

Second Generation Groups

Paula David, MSW, Coordinator, Holocaust Resource Project, Baycrest Centre

Adult children of Survivors are as individual and unique as their parents. They grew up in homes where the Holocaust was not another school history topic, but a real and influential presence. As children, many heard of family histories cut short, and they heard of tragic and senseless loss. Others heard only weighty silences, witnessed pent up sorrow and were unclear about its source. Many understood their parents were "different," not just because they were immigrants with the associated differences, but due to a sorrow that permeated the air. As these children matured, they began to learn and read about the Holocaust and to piece the fragments of their family stories together. They focused on their parents' successes and struggles and continued to support them as they age.

In recent years, adult children of Holocaust Survivors have worked hard to reclaim their own experiences and feelings in order to combat labeling and diagnosis that manifests as a result of the symptomology. Adult children have raised social consciousness; they often express a collective identity and the need to work together to discuss, clarify and explore how they feel about their relationship to the Holocaust and their identity as children of Holocaust Survivors. These adult children, known as the Second Generation also emphasize strength, vitality and a high rate of academic, financial and professional success.

Today, they are caring for aging parents. As they also deal with their own mid-life issues, they look to each other for mutual support, understanding and insight. They are also looking to the future, and - often in the names of their lost families -- they commit themselves to Holocaust education and to maintaining the Survivors' legacy. Around the world, the adult children of Survivors are forming groups to provide this mutual aid and support, to educate the next generation and their communities.

Second Generation self-help and education groups can be successful within a variety of formats and themes. The only prerequisite is a common goal and a commitment to be open and accepting of differences. Indeed, most group members discover many commonalities. Whether they have already lost their parents, are providing care to aging parents, are maintaining long distance relationships or are involved in Holocaust education, there is much to talk about and discuss.

Support Groups

This type of group best reflects a self-help paradigm, providing peer support and mutual aid in relieving the stress related to difficult life situations. A formal support group requires a trained facilitator who will ensure a safe forum for the disclosure of potentially painful issues. The commonality in this type of group is family history, and so there will potentially be a range of different ages, lifestyles, religious observance and economic backgrounds in the participants. The facilitator must work with the group to continually clarify both the purpose and the desired outcomes in order to have a successful support group.

Other groups may be less formal and require a commitment by a group of friends to meet regularly and discuss the issues. Both types exist in large cities throughout North America, Europe and in Israel. An adult children's group might deal with issues of aging, caregiver issues associated with their aging parents, or the recent loss of an elderly parent. The children of Survivors are themselves growing older, and by virtue of their parents' shared trauma, they often have unique commonalties and Holocaust perspectives. Not only do these "children'" often have ambivalent and unresolved feelings towards their parents toward their parents' experience, the threat of a parent's death increases their sense of vulnerability. Loss, whether expressed or repressed, has been a shared theme in their lives.

Group members share their life narratives, their perception of the impact of the Holocaust on their lives, and how this particular trauma has informed their existence as parents, spouses, children and in their careers. The level of mutual acceptance and support within in these Groups is remarkable, especially considering the range of individuals involved. The group may be used as a surrogate family, and strong bonds -- based on mutual insights into a unique heritage - often develop and grow.

Health Care Professionals as Caregivers

A Multidisciplinary View

Linda Jackson, MSW, Director, Social Work Department, Baycrest Centre

The following section of the manual was developed through contributions from more than 14 different professional groups and service providers working at Baycrest Centre for Geriatric Care. It includes input from practitioners at a senior support agency serving individuals living in the community, and from academics at Canadian colleges and universities.

This may represent the first time that perspectives on this topic have been compiled in a single document, with contributions from individuals who have firsthand experience working closely with Holocaust Survivors and their families.

Providing care and support to Survivors of the Holocaust can be a humbling, remarkable and sometimes overwhelming experience. At Baycrest Centre, the Holocaust is present everywhere -- many residents, outpatients and staff are Survivors or family members of Survivors. Many of those who contributed to this section underestimated both the depth of their knowledge and the importance of their contribution. We hope that by their participation in manual, these people will share their learning with others in their own disciplines and throughout the broader, caring community.

Each contributor has provided some background on the role of his or her specific profession in caring for Survivors and their families. Case studies illustrate the issues through various professional "lenses," and also describe approaches, interventions and strategies that have proven to be helpful. Reading through the various sections, it is apparent that we need a common understanding of the historical events of the Holocaust and their impact.

Most important is the fact that every Survivor is a unique individual with his or her own personal experience. As providers we need to respect this uniqueness, be prepared to listen and be sensitive about what is being said - and also what is not being said. In dealing with clients and families, we must always communicate our roles clearly, describe what we are doing and why we are performing a task or intervention.

We must also have a good understanding of the normal aging process, and also the particular challenges that may face aging Survivors. As health care providers, we must value the role that family members play in the lives of the Survivor and encourage their participation in care planning and care provision. We must be sensitive to the impact of declining health, hospitalization and possible long-term placement on family members who may feel they have failed their loved one by involving others in the care process.

Organizations also need to understand the impact of working with Survivors for staff, students and volunteers. Adequate supports and educational resource must be available so caregivers can provide the best possible care.

The following perspectives clearly identify that Survivors, like other older adults, need compassionate, high-quality care and support. Most importantly, they deserve recognition for the obvious strength and resiliency which led them here.

Ethical Considerations in the Provision of Healthcare to Survivors

Marcia Sokolowski, M.A.,C.Psych. Assoc., Ph.D Candidate (philosophy) Clinical Ethicist, Baycrest Centre

As health care workers we have ethical responsibilities that underlie the services we provide, and that also influence the quality of relationships we form. Whether or not we are members of professional bodies that provide us with formalized ethical guidelines, we are responsible for conducting ourselves according to our notions of right and wrong, and to what constitutes sound ethical practice. We are constantly making ethical decisions and are held accountable to their justification. We are governed by ethical principles that guide our behaviour towards each other and with patients and their families. This discussion will focus on ethical responsibilities towards our patients, particularly the role of ethics in the treatment and care of Holocaust Survivors.

In general, the principles most health care providers adhere to include a responsibility to respect the patient:

- to treat him/her with dignity
- to encourage independence and autonomous decision-making
- to do good in the name of serving the patient's best interests
- to do no harm, and
- to apply some measure of fairness in allocation of resources.

At times, differences of opinions may arise among health care professionals themselves or between them and their patients and their patients' families about what indeed is in the patient's best interest, or how to define respect and dignity. What one person defines as a "harm" may be seen by others as a "good." Religious and cultural beliefs may account for some of these differences, and they must be understood and taken into consideration. In addition, it is essential to understand each patient's "story" and to understand the particulars of it in relation to the care being received.

Survivors' Perceptions of Health Care Providers

Each Holocaust Survivor has his or her own unique story of hardship and survival. While there is no one model of care that fits all patients, ethical care requires all caregivers to be sensitive to certain facts about all patients' stories. In the case of the Holocaust Survivor population, there is a duty to understand past experiences and their influences on the patient today.

In order to do so, it is equally important to understand some relevant historical facts about the role of medical personnel in the horrific crimes and torturous experiments that were committed under the Nazi regime of World War II. One must be open to learning what beliefs Holocaust Survivor patients have about how they might be cared for, or perceived possible abuse by caregivers, given their own knowledge and personal experience of power abuse during the Holocaust.

Holocaust Survivors in geriatric facilities are as unique in their ways of being in the world and relating to others as are any other people. However, there are certain past realities that influence their current lives, often in very dramatic and poignant ways. Health care providers have a duty to understand as best as possible the patient's story, whatever that may be. And that story includes what each patient's beliefs and ideas are about how they would like to live out their lives, and how they would like to die.

Any fears Holocaust Survivors harbour about possible mistreatment by medical staff due to medical staff's role in Nazi medical experimentation and death selection must be respected and understood. And ethical care also includes sensitivity to how the patients' stories are elicited and an honouring of patients' wishes to keep some or all of their stories private.

Role of Medicine during World War II

Heath care providers working with Holocaust Survivors have a duty to understand some of the "medical" events that took place during World War II. During World War II Nazi physicians and scientists upon many present day Holocaust Survivors and/or their families performed highly unethical and torturous medical experiments. They were stripped of their humanity and considered to be non-persons, mere guinea pigs to be experimented upon in order to gain scientific and medical knowledge. Many were annihilated as they were considered to be contaminants of the pure Aryan race or defined as "life unworthy of life". During his internment in a camp, a Holocaust Survivor physician pointed to the chimneys in the distance and asked a Nazi doctor, "How can you reconcile that with your Hippocratic oath as a doctor?" The Nazi doctor replied, "Of course I am a doctor and I want to preserve life. And out of respect for human life, I would remove a gangrenous appendix from a diseased body. The Jew is the gangrenous appendix in the body of mankind."

Physicians claimed the largest representation within the Nazi party amongst all German occupational groups. Having defined people as an underclass or a risk to the genetic or racial health of the population, medical science deemed the so-called "inferiors" to be appropriate experimental "subjects." German law did not even permit the kind of research that occurred to be done on animals. Many of the scientific and academic organizations and institutions that had previously been involved in the development of modernized biotechnology and medical science education and practice were participants in the evils practiced by the Third Reich.

Treating Aging Survivors

Tragically, some of our Holocaust Survivor patients have themselves been victims of inhumane medical experiments in the past. Others were deeply impacted by the experiences of loved ones. We need to be very aware of the possibility of emotional triggers that arise from being hospitalized, including flashbacks to past scenes of torture and abuse. It is easily understood, in this context, how patients might be terrified of yet again being subjected to hideous abuse by caregivers in power.

It should also be remembered that many Holocaust Survivors being cared for in a geriatric facility may be experiencing some degree of dementia. Some might find their long-term memories intensified, leading to nightmarish images, feelings and fears caused by their Holocaust experiences. At a minimum, we are professionally and ethically justified to question ourselves about what that means in terms of providing quality care. Do the atrocities of the Holocaust mean we as professionals must assume extra and /or different duties in how we provide care for Survivors? This is a question each of us must struggle with, in order to provide ethical justification of our professional behaviours.

Conclusion

Earlier some ethical principles to be considered in providing health care to patients were mentioned. What meaning do they have in the context of each unique Holocaust Survivor? What do they mean to health care providers working with a Holocaust Survivor patient? How does or should one understand care providers' ethical obligations and duties as they care for Holocaust Survivor patients? This is a story at a minimum about horrific power abuse. What meaning does this have for the elderly Holocaust Survivor patient confronted with health care workers? And what obligation does the caregiver have to pay particular attention to issues of power, and to how power differences might be perceived by a particular patient?

Answers to these questions are not provided here. But it is part of each health care worker's professional and ethical responsibility to address these questions and consider them in light of the principles mentioned as they care for aging Survivors.

The Social Worker's Perspective

Paula David, MSW, Coordinator, Holocaust Resource Project, Baycrest Centre

The social worker might work with older Survivors in the community and the long-term care setting. The primary roles of the social worker are to provide counselling to either the Survivor or family members, and to help them navigate the health care system. The social worker coordinates services with client needs to optimize care. He or she would be involved as long as clients or family members use community or institutional services.

As Survivors grow older and confront the stresses and challenges of aging, they potentially face an exponential increase in vulnerability. In turn, their children also must cope with their parents' issues around death and dying, along with their own fears about losing a parent.

Major illness, cognitive impairment and institutionalization will have a critical impact on any older adult and his/her family members. But for the Holocaust Survivor there are additional elements. The DSM-IV diagnosis of Post Traumatic Stress Disorder is based on six criteria, including re-experienced trauma and disturbing symptoms. The categories take into account that symptoms may remain latent for many years following the trauma, sometimes occurring in the wake of a "trigger" event. Aging, its related illnesses and inevitable death may be laden with such triggers for elderly survivors and their families.

Social workers must be aware that Survivors may respond to counselling as a sign of personal weakness. When the War began, they had to fend for themselves and it was vital that they appeared strong enough to do so. Allowing a professional to see their vulnerabilities may have the opposite effect that was intended. Family members, in their desire to protect their parents from these fears, may also be reluctant to accept outside help. The social worker must develop a comprehensive understanding of the varied experiences and history of the Holocaust, and also put the individual's Holocaust experience in context of his or her entire life story. Having an historical and academic understanding of the Holocaust will help the social worker deal with whatever current issues are relevant to the client. Having an accurate perspective on his or her own personal reaction to the horrors of the Holocaust will also help the social worker support the client.

Each case is unique because it illustrates the diverse ways that individuals and families coped in the face of inconceivable obstacles. At the same time, each case seems similar to others in that the range of traumatic events lies well outside any definition of "normal." The social worker must deal with the client's pain and other issues, as well as his or her own personal reaction to the difficult legacy of the Holocaust. Issues of tolerance, religion, culture, ethnicity, man's inhumanity (and heroism) in the face of extremely difficult circumstances, must be dealt with in the context of client experience as well as the worker's personal background and emotional response. Survivor narratives can be brutally devastating for the listener, either due to horrific detail or through silences that can take the imagination to inconceivable places. The social worker's model of psychosocial educational interventions is particularly suited to the multifaceted needs of Survivors.

Case study: Mrs. S.

Mrs. S. had survived in two concentration camps with her husband. Their three children did not survive. After the War, Mr. and Mrs. S. came to Canada where they had a daughter and built a successful business.

Mr. S. died suddenly three years ago. Now, at age 83, Mrs. S. is suffering from Alzheimer's' Disease and has just been placed in a nursing home. Her daughter, who was always exceptionally close to her mother, telephoned her mother several times a day since she became a widow. Once she was admitted to the home, Mrs.S. began calling out to her dead children and became very agitated when her daughter visited, begging to be taken home.

Mrs. S.'s daughter was heartbroken that she couldn't care for her mother at home and that circumstances had forced her to break her personal vow that she would never "abandon" her mother. She had wanted to protect her mother from any further pain. Mrs. S.'sr daughter felt so guilty about the placemen that she began to visit less often and to withdraw emotionally.

Mrs. S. responded to her daughter's absence by striking out at the nurses, accusing them of "locking her up" and comparing the nursing home to Auschwitz. The nurses were unable to provide any effective reassurance or comfort. At night Mrs. S. cried and talked to her dead children. She told them "they" were trying to kill her and that she would see them soon. The daughter was devastated and reduced to tears every time she visited.

Social Work Issues Raised in Case Study

- multiple losses capped by recent loss of spouse
- small nuclear family leaves full burden on daughter
- no other living family besides daughter
- placed in a long-term care institution where the setting is unfamiliar
- daughter withdraws and the people providing care are not familiar
- striking out at nurses because client is "triggered" by all these issues

Impact of Chronic Illness

As Survivors advance in age and as their health care needs become more complex, they come into contact with hospitals, nursing homes and institutions for the aged. Relocation to these settings can potentially elicit difficult reactions associated with their early life exposure to extreme pain and loss. For instance, if a Survivor of the Holocaust was involved in Nazi medical experimentation during the War, then exposure to medical care and surroundings may be difficult reminders of early life trauma. Such feelings are likely to persist when the Survivor confronts the natural realities of aging. Even under the best conditions, institutional placement and the restrictions involved can be traumatic for Survivors of the Holocaust. Such exposure may elicit feelings of being uprooted from familiar surroundings. Also, the strict schedules, medical care and communal living may trigger the traumatic memories.

Social workers must also understand the impact of normal aging on individual Survivors. As they age and are confronted with new losses -- declining personal health and ability to function, plus the natural deaths of friends and family - Survivors are easily reminded of their earlier tragedies. Yet even in the face of such challenges, these individuals tend to demonstrate incredible capabilities that allow them to lead their lives with integrity.

In the early years of World War II, the Nazis immediately killed the elderly and the ill. As a result, many Survivors have a deep-seated fear of both age and infirmity. The reality of chronic illness is that the individual becomes dependent on others for aspects of care. This may be especially difficult for Survivors who learned to be independent and to look after their own needs, and those of their families, without help. It was this determination and ability that allowed them to build new lives after the War. For Survivors, vulnerability is often synonymous with death.

In the case of Mrs. S., she could be helped by ongoing reassurance as to her personal safety and reminders that she is surrounded by people who care for her.

Alzheimer's Disease is a devastating illness that wreaks havoc in any family, but for Survivors it can be particularly painful. With the loss of short-term memory, they may forget their joy and pride in post-War accomplishments such as having built new lives in new countries, having raised and educated responsible and caring children, and having lived to see and to adore their grandchildren. As their minds deteriorate, they may be unable to control the intrusion of painful, long-term memories, and traumas of years past may become their only reality. Repeated orientation to time and place may be helpful. For Mrs. S., it would be reassuring to show her photographs and other visual reminders of her recent and current life and interests. This might help her understand that those around her know who she is and care about he well-being.

Impact of Long-Term Care

Although institutions may try to create and provide a home-like atmosphere, in reality, those who live in long-term care facilities are separated from their homes and do lose some degree of autonomy. The environment must support the needs of many different people, and as such, it can be a strange and frightening place. Regardless of where Survivors spent the War years, they lived in chronic uncertainty and in environments where they had no control. As a concentration camp survivor, Mrs. S. would have memories of controlled chaos, pain and fear in an environment where she was surrounded by death and cruelty. It is understandable that she would feel safest in her own home surrounded by people she knew well and trusted.

While caring staff may be attentive to her individual needs, Mrs. S. might respond negatively to the home's set routines and rotating staff. She may also react fearfully to the presence of residents who may be ill and who are certainly strangers to her. From her own perspective, long-term care may feel like the ultimate cruelty at the end of a traumatized life.

Once again, she has been forced to leave her home and familiar environment and become dependent on strangers for her basic needs. Her dementia could further confuse her perceptions and the reality of the care she receives. She should be approached calmly and gently at all times. Staff, volunteers and visitors should be reminded to identify themselves to her each time, and to explain their intentions to provide care. Verbal reminders and cues indicating that her family and her story are known to them may also make her feel safer.

Impact on Family

In many cases, adult children of Holocaust Survivors experience a transmission of their parents' early life trauma. The usual mixed feelings about their parent's changing health and the potential for institutionalization are exacerbated. Having a loved one suffer from Alzheimer's and require institutionalization is difficult for any family, but may be particularly painful for Survivor families. The Second Generation often share a sense of loss and burden themselves which is directly related to their parent's traumatic experiences. It is only natural that they would wish to shelter them and protect their mothers and fathers from further pain and trauma. But sadly, there is no shelter from the negative aspects of aging and unforeseen health complications. Often adult children are painfully frustrated as they must watch their parents re-live Holocaust nightmares.

While Mrs. S.'s daughter may have made a commitment never to institutionalize her mother, she was unprepared for the complexity of care that her mother required. Eventually she came to realize that her mother's needs would be best met in a long-term care facility. The daughter must be reminded of this whenever her mother faces difficulties in the facility. It is important to encourage her participation in her mother's care and in all care planning, and to give her the opportunity to teach the care team about her mother's individual needs and insecurities. Social workers should realize that for Mrs. S.'s daughter, this is probably the first experience with care giving. After all, her parents were the only survivors in both her maternal and paternal families of origin, and her father died suddenly. This means the daughter never visited a long-term care facility before, and -- growing up without grandparents, great aunts and uncles -- may not have had any experience with an older adult.

This daughter needs support and education about normal and abnormal aging, and might also benefit from counselling over her fears and her perceived inability to protect her mother. She also needs ongoing reassurance that staff understands Mrs. S.'s difficulties and the challenges she herself faces as the only member of the family.

Family Involvement and Communications

Survivor families, in their effort to protect elderly Survivors and lessen an elderly parent's trauma, may often appear over protective. This should be recognized and appreciated for what it is - the normal response of a caring family to an abnormal family story. Psychosocial support and counselling are crucial to carry family members through difficult times in their parent's adjustment to institutional care.

In situations of strained family relationships, Survivor families may be coping with powerful feelings of guilt when their elderly parent becomes ill. Often, the inability to protect their parent from the challenges and pain of aging may cause extreme responses from relatives. They may withdraw, unable to cope with the current situation. They may have the opposite response and find it difficult to leave their parent's side, feeling they are the only ones who can adequately care for a parent.

Family members need support to define their personal boundaries and abilities regarding their parent's care needs. In the case of Mrs. S., her daughter needs support in defining where she can contribute meaningfully to her mother's care and where she can't. Further understanding of dementia and frequent communication with professional staff may lessen her anxiety, since she knows that staff are doing the best they can.

Coping with Death and Dying

With the decline of a Survivor parent adult children may be dealing with the challenges of death and dying of a loved one for the first time. Issues of separation, intimacy and bonding are impacted by the history of multiple losses that has permeated all aspects of family life. These children also have to face their parents' mortality and the concept that even Survivors must die someday.

Compounding this anxiety is a paradoxical familiarity with the concept of death, having being raised in a unique environment where genocide was very much part of the fabric of family life. The loss of a Survivor parent also signifies the loss of the last living link to the family history. The legacy of the Holocaust -- from the horrors of the genocide to the courage and resilience of the

Survivor - now rests with their children. Aware of both the burden and the blessing of this legacy, many children of Survivors cope with anticipatory grief and mourning that is exacerbated by illness and aging. These potential issues related to death and dying may define the Survivor's family system, and it's vital that they be understood by clinicians involved in their care.

Staff Coping with Emotional Impact of Caring for Survivors and the Potential for Burnout

Listening to Holocaust-related client narratives (and also to the eloquent silences which are common in these families) is both extremely challenging and rewarding for social workers. Many Holocaust Survivors respond well to narrative therapy, "storying" or empathetic listening.

The Holocaust and its related traumas are not the only important events in a Survivor's life, but they are likely pivotal ones. The social worker must be able to help the Survivor to view his or her personal history as one with many facets and many chapters. Life before the Holocaust and the challenges and accomplishments of the pos-War years are also part of an individual's narrative. The social worker can assist the client through a focused therapeutic intervention coupled with an opportunity to produce a narrative that can reconstruct a "story" and a reality which is comfortable for the client. The deconstruction of personal narratives, supported by visual or auditory aids, may allow older Survivors to share their stories with the social worker. As with any elderly individual facing her mortality, the value of the life narrative cannot be underestimated. Social workers must recognize the impact of counter transference with Survivor clients and their families. The depth of their pain and the burden of their loss can also traumatize the social worker. Understanding that feelings of helplessness, anger and often guilt over the enormity of the client's losses can be viewed as normal reactions to an abnormal situation.

The process of providing empathetic listening must be balanced with planned supportive team review and ongoing support, both from colleagues and in the form of ongoing professional development. Not only is it therapeutic for the client to recognize pre- and post-War narratives, it is important for the social worker to view the client's Holocaust experience as a chapter in a life narrative.

The impact on the person who supports the telling of this narrative should not be underestimated. Empathetic therapeutic listening to Survivors' stories is both a privilege and a clinical challenge. In order to maintain composure, professionalism and effectiveness, the social worker must have access to a debriefing mechanism, either within the care team or with other colleagues. It is well documented that clinicians, in order to work effectively with victims of violence, torture and/or abuse, require ongoing professional development, smaller caseloads and collegial support. The Holocaust Survivors experienced all of the above, and the social worker must recognize the burden of their stories and the necessity for support in order to maintain clinical competence.

Institutional Care vs. Community Care

Many of the difficulties experienced by Mrs. S's daughter' could have been alleviated if she had received psycho-educational support prior to her mother's cognitive decline and institutionalization. For example, community social workers could have directed her to specific Second Generation resources and support groups, as well as general information regarding normal aging. Had she understood the many issues and emotions shared by adult children of Holocaust Survivors, she might have been less traumatized by her mother's institutionalization and decline.

Although Mrs. S. could no longer be supported in the community, some Survivors with serious health concerns are able to manage with in-home supports. The community social worker plays an instrumental role in managing such cases - for example, educating and supporting the in-home care providers on the unique circumstances of the Survivor's past and offering advice on how to provide responsive and sensitive care.

Tips for the Social Worker

Support the Survivor. Careful placement and/or treatment should not be confused with War-time incarcerations. If the patient cannot differentiate, environmental cues and supports should be introduced into the environment to help keep the person oriented to time and place. Family photos, personal treasures and reminders of post-War pleasures should be readily visible to help balance traumatic memories. The importance of available "listeners" -- staff, family, and volunteers - to hear the person's stories cannot be overestimated. At the same time, Survivors who desire not to speak about upsetting life events must be respected.

Support the family. As with their parents, it is also crucial to recognize the range of individual issues and perceptions of the Holocaust from the perspective of Survivors' children. All family members are considered key participants in the care plan for their aging family members. In the case of Survivors, there are unique family issues that must be considered and recognized by staff. Like their parents, the children of Survivors cannot be assessed as a homogeneous group, and professional staff must look to them for clarification and direction. Social workers must remember that some children need support as they accompany their parents on the difficult journey of aging. Extremely close and protective parent/child dyads may compound the challenges. It is also important to remember that the nuclear families of Survivors are often much smaller than the norm, and adult children have fewer resources to draw on in difficult times. The social worker must be aware of families' abilities to cope with the demands.

Educate the family. Understanding both normal and abnormal aging can help the family cope with the mental and/or physical deterioration in their loved ones. Understanding how aging, illness and changes in the environment can trigger memories of the Holocaust will also help the family not to feel personally responsible. The list of triggers in "Part 1: Understanding Survivors" is not only important for professionals working with aging Survivors. It should also be shared with family members as well. If an older person becomes cognitively impaired or just disoriented, even a familiar home environment can suddenly seem threatening. Once family members are aware of the triggers and their impact, they become a valuable resource for the professionals who providing care to their loved one.

Counsel the family. Helping the family understand the complexities of the care giving role and the unique role the Holocaust may play in their own world view may give them valuable insight into their parent's situation. By understanding how Survivors react, we further our understanding of the Second Generation - the adult children of Survivors. Evidence suggests that many adult children of Survivors experience an intergenerational transmission of trauma from their parents to their own. Writings on this subject suggest the presence of a unique bond within Holocaust families. Many Survivors perceived their children as their reason for survival and their reason to keep living, even through normally hard times. These children of aging Survivors may experience guilt when they attempt to separate from their parents in adolescence, when choosing a mate, when taking a job in another place -because of the potential to impose pain on parents who already suffered great loss. A common reaction may be intense involvement on the part of the children through this difficult phase of aging.

The effects of the Holocaust on adult children of Survivors, are varied and complex. Research has demonstrated the uniqueness of bonds in Holocaust families. Families may be extremely close, or conversely, may develop strained relationships, making it difficult for adult children to respond effectively when parents require their help. All families are unique and have different responses to coping with the scars of the Holocaust. What they have in common is that they all bear the scars of that event. A Second Generation Group or Survivors' Group for spouses might help family members find a supportive community for their unique challenges.

Educate the staff. The health care team must know about the person's background in order to appreciate both his or her fears and behaviours. In the case of Mrs. S., perhaps her daughter could create a door poster for her room, with photos of her parents as a younger, healthier couple in happier times. Other photos could show the daughter herself and the Survivor's grandchildren, if there are any. The staff must be made aware both of Mrs. S.'s Holocaust history and --- equally important - her post-War accomplishments. All staff members who have any contact with a Survivor client must be aware of the triggers and their impact on perceptions of safety and well-being.

Support the staff. As the staff becomes aware of Mrs. S.'s War- time experiences, they may be overwhelmed by their inability to comfort her. Staff will need to vent their anger and frustration over what has happened to their patients. Even identifying the designated client population as "survivor"' seems at odds with the everyday realities of aging and mortality. For professional caregivers working with this population, the history of strengths and diversity of client need, the depth of long-standing emotions, and the impact of post-traumatic stress on entire family systems necessitates ongoing learning, peer support and clinical supervision. Staff must be aware of the challenges and relevant supports.

Support the team. This can be achieved by creating a caring community for Survivors, all other patients, staff and family. Survivors in particular have coped with danger and fear within their community, and as much as possible should be supported in feeling safe within the long-term care environment.

Physicians Caring for Aging Survivors

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Medicine and the Holocaust: History

Seventeen years ago a landmark event in Holocaust history occurred with the publication of Robert J. Lifton's book, The Nazi Doctors. In that book Lifton detailed the nefarious activities of some Nazi doctors with a particular emphasis on Dr. Josef Mengele. While Lifton's book was extremely important in awakening interest in the subject of medicine in Nazi Germany, the focus of the book was limited to a few doctors. Unfortunately, the title gave the misleading impression that the few doctors described by Lifton represented the Nazi doctors.

Three years after the Lifton book was published there appeared another book in English by the German-born Canadian scholar Professor Michael Kater entitled Doctors Under Hitler. Kater's book went far beyond Lifton's work in that it documented the ubiquitous involvement of the German establishment in the crimes of the Third Reich. Kater emphasized the post-War careers of physicians involved in the infamous activities of the Third Reich. According to Kater, many of those same physicians went on to assume influential positions after the War. He described the pervasive Nazi influence in the Federal Chamber of Physicians of Germany. Among the four post-War leaders of the German medical profession, three were former members of the SS and SA. Amidst the recent revelations concerning the role of banks, insurance companies and major corporations during the Third Reich, little attention was paid to the role of medicine, including the parts played by universities, research institutes and pharmaceutical companies in the terror of the Hitler regime

In 1993 the world learned that a leading German doctor (and former president of the doctors' chamber) who had been a member of the SS and was linked with the Nazi euthanasia program, was appointed president-elect of the World Medical Association for 1993-94. After being exposed in the world press, Professor Sewering resigned from his position with the world body, claiming that he was the victim of an international Jewish conspiracy.

In the 1990s it was disclosed that leading Austrian institutions, in particular the University of Vienna, the Vienna Psychiatric Hospital and the Vienna Museum of Natural History, had kept the physical remains of victims of Nazi terror. Not surprisingly the victims have received little consideration in all this. Perversely, the victimization by German doctors continued long after the end of the War. Holocaust Survivors seeking compensation from Germany as part of reparations were forced to undergo medical evaluation by doctors who had themselves been involved in the medical crimes of the Third Reich. It is not surprising that, based on history, many Survivors would be cautious about physicians.

Current Practice Approaches

The community physician who works with elderly Survivors must consider a range of variables. Whether or not the patient is cognitively intact or impaired will impact on the reciprocity of the relationship, on the amount of disclosure, and on the person's response to illness and treatment. Some impaired Survivors may perseverate over traumatic experiences; others are fortunate enough to retain clearer memories of happier times. Even cognitively intact patients may choose to "selectively" recall their War traumas or, conversely, to view them as the primal cause of their current pain.

Regardless of cognition, some Survivors may focus on their Holocaust memories and others choose to de-emphasize this time in their lives. It is important to individualize both the response and the direction of patient history based on what the patient is prepared to disclose. If the patient is prepared to tell you his or her story, the physician should be prepared to listen. The story may be a key to gaining insight about the person. A further obligation is to document the patient's story so that it will not be lost. Often Survivors, in the course of discussing their medical histories, their current health status or even their pending mortality, will reveal personal history to their physician.

Whether these revelations become part of the patient record or are passed along to other staff, the Survivors' stories are critical in understanding and coping with certain unique clinical challenges. Even as we respect the individual's right to confidentiality, we can learn much from these patient narratives.

Their narratives and their ability to remember is an individual matter that cannot be generalized. The main commonality is one of loss. Many Survivors who were married and had young children at the outset of the Holocaust emerged from the chaos to learn that their spouse and children were no more. Many remarried, often to other young widows and widowers of the Holocaust. Now, the only reminders of their former family's existence are ephemeral memories; there are usually no documents, no photographs - nothing.

The Survivors began new lives and new families, but they were ever mindful of the horrors that had consumed their loved ones. For the newly married couples, there were no parental role models, no loved ones, no grandmothers to share their experiences raising and loving children. Childhood had been destroyed. Family had been destroyed. They are the Survivors, the ones who endured the greatest mass slaughter in the history of humankind. The men and women who emerged from hell, who faced daily encounters with death and destitution, came out alive. They may have come out alone, too, but the fact is, they had survived.

An eloquent spokesperson who has dedicated his personal and professional life to the Survivors is the Vancouver psychiatrist Robert Krell. He is a Survivor from Holland who, as a child, was hidden with a non-Jewish family. He wrote in the Canadian Medical Association Journal about of one of the ironies of being a Holocaust Survivor: while he did not lose anyone in his family until his father died at age 82, his life has been filled with death: "Because my grandparents were murdered I had neither the privilege of sharing their lives nor the experience of their natural deaths. My aunts and uncles, who were all under 30 years of age, were also murdered. By the war's end there was no one left who was older than my parents".

The Survivors emigrated to new countries and tried to rebuild their lives, marrying, having children, forming new families and new communities. These Survivor couples are the Adams and Eves of their families. They represent Genesis; the creation of a new beginning. The Survivor parents, the first generation, represent the only history. They are the sole foundation of the family. As Survivors, they have an aura of invincibility and immortality. As Robert Krell described it, there were no grandparents or other relatives who survived to old age and then passed on. The Survivors were all from the same generation, but it was a generation without elders. Their children would not experience a death in the family until their own parents, the Survivors, the invincible ones, the foundation stone of the reborn families themselves, became ill and died.

Those Survivors who were in their late teens and twenties at the time of liberation are now in the last stages of their lives and facing the inevitability of their own mortality. . The few adults who escaped from the ghettoes and camps often survived by hiding in the woods and forests. The relatively few Survivors from the concentration camps and the ghettoes were mainly young adults and older adolescents. For these young people, the adult role models were SS guards, camp kapos and fellow inmates. It is imperative that physicians understand the scope of trauma and loss that every Survivor, regardless of individual circumstance, suffered.

Upon liberation these people continued to live in a form of captivity as so-called "displaced persons". Upon being freed, most discovered that they were alone. The Survivors found that their families, homes, communities, support systems had been destroyed. There was nothing and nobody. If the Survivors happened to learn where their parents, siblings, spouses and children were murdered, they did not know when they died. There are no discrete graves. There are no headstones. There are no dates known for the recitation of Kaddish (the Jewish prayer for the dead). There are usually no physical remnants of a past life such as documents or photographs. There is only a vacuum. Nothing.

This is what the young adult Survivors brought to parenthood as they began new lives in new countries. They overcame insurmountable odds and made remarkable adjustments and recoveries. They seemed invincible. Today their adult children are facing the terminal illness and death of their invincible Survivor parents. These children may seem over-protective, yet at the same time, they may believe their parents can beat all the odds, including aging and illness. Physicians must understand that Survivor parents are often the children's only relatives. These adult children have a very real fear of losing their whole world in the face of parental death. Their resistance to care plans presented by the physician may in fact be a reflection of their inability to let go.

In 1981, 36 years after the end of the Holocaust, a child Survivor of Buchenwald concentration camp addressed the World Gathering of Holocaust Survivors. Known in 1945 by his Polish name of Lubek Lau, in 1981 he announced to the world gathering, "My name is Israel Meir Lau. I believe I am the youngest Survivor of Buchenwald. I was eight years old at liberation. My father was the last Rabbi of Piotrowsk in Poland and was killed in Treblinka. My mother died of hunger in Ravensbruek concentration camp".

Three years later, Lau reflected again on his experience in an interview. He said: "I was born twice, first biologically in June 1937 in Pietrkow, and then spiritually upon my arrival in the Holy Land on July 17, 1945 ... . I was eight years old then. I speak of a second birth because it is hard to conceive that after experiencing Buchenwald, the long marches, the hiding and the cold, that such a little orphan could become a little boy wearing blue and white shorts, playing soccer and marbles. I had walked among the dead and had helped push carts piled high with corpses to the crematoria. And yet, the same little boy had learned to sing again and to recite the alphabet. Could I actually be the same person?"

When asked by the interviewer to tell more about his experience, Lau responded: " No I don't want to continue my story. At all types of ceremonies I talk about the deported people, about their sufferings and their experiences, but in general terms only. I never reveal anything about myself ... I cannot."

Lubek Lau and the other child Survivors of Buchenwald were taken in by a children's rescue society in Ã‰cous, France. One of those child Survivors, Romek Waisman made this observation about the French people he met: "To their horror (they) ... discovered quickly that we were unusual to say the least, a horde of suspicious, distrusting, rebellious and hostile children - as if from some other planet. They tried to give us salad to eat. Did we survive to be fed like rabbits? Then they gave us smelly Camembert cheese. Why were we given food that smelled foul to us, as if it should be thrown away? We learned over time to appreciate these delicacies.

"Then we were tested physically and psychologically and pronounced beyond redemption. It was at Ã‰cous that we were told we would not recover. We were said to be cold and indifferent. Some professionals believed we were true psychopaths. In a sense, were they not correct? How do you react to watching humanity and humans destroyed before your eyes, to losing all your family and friends? It was not easy to become humane again. People said that we were "les enfants terribles de Buchenwald" and not redeemable. The first time I was asked my name I blurted out my concentration camp number. No, it is your name we want. It was the first time in years that I realized I had a name." (Hemmendinger and Krell, 2000)

Lubek Lau is now Rabbi Israel Meir Law, the former Ashkenazi Chief Rabbi of Israel. Romek Waisman who almost forgot that he had a name is now known by the name of Robbie Waisman and lives in Vancouver.

These are the Survivors who were able to rebuild their lives and their families through marriage and conception. An unknown number who survived were not so fortunate. They are the women who were unable to conceive after the War ended. Many were victims of Nazi eugenic and racial sterilizations; these were medical surgical procedures imposed for the main purpose of preventing the conception of a child by a Jew. Some young women in concentration camps were sterilized for purpose of sexual slavery to Nazi officers. Thus the Aryan officers were free to sexually exploit the women without having to worry about the possibility of conceiving a child by a Jew.

Needless to say, women who survived these experiences are not eager to disclose the shameful encounters that scarred their lives forever. We will never know how many women were brutalized in this fashion. These scars are best exemplified in a brief report that appeared in the British Medical Journal (February 2000). The report documents the experience of Dr. Roni Peleg, a resident in family medicine at Ben-Gurion University in Beer-Sheva, Israel.

Peleg describes his encounter with a 72 year-old woman who presented in the emergency room of Soroka Hospital in Beer-Sheva complaining of abdominal pain. When asked if she had undergone any previous operations, the woman answered in the negative. However, the abdominal examination revealed a large midline scar below the navel. When asked why she hadn't mentioned the surgery the woman looked embarrassed and said, "How do you think I stayed alive? I had a sterilization done by the Nazis, you see? During the war I lived in a whore house and this is how I survived."

The BMJ report continues: "That same night, a few hours later, another woman came to the emergency room complaining of abdominal pain. She was 74 years old and married without children. She seemed young for her age, and wore heavy makeup. A tattooed number was seen on her arm, typical of the numbers inscribed by the Nazis during the Second World War. When asked about previous operations, she also answered in the negative. When asked directly about past gynecological operations, based on the experience with the earlier case, she hesitantly said, "Yes, I had to have it in order to survive during the Holocaust. I was a whore in a Nazi whore house."

This article underlines both the scope of the tragedy and the importance of sensitive inquiry. These are just a few examples of the memories and scars that the Survivors and their families continue to bear. There are many more secrets that are so painful and so shameful to the victims that we will never know what happened. All we may encounter are the agonizing scars without ever knowing or truly understanding what really happened to that person. The caring physician must be aware of the emotional as well as the physical wounds and, with or without a comprehensive understanding of the individual's experience, must commit to no further victimization or cause any feelings of shame.

Given the profound trauma experienced by the Survivors and the role that medicine played in the origins and perpetuation of that trauma, the physician caring for Survivors has a special responsibility. He or she must find ways to understand how the exercise of professional power can affect vulnerable people who seek care, cure, and compassion from doctors and the health care system. Framing the response to this question over time is the moral responsibility of the professional and academic leaders in medicine. They must examine the experience of medicine during the Holocaust, the impact on the victim, and the implications on the ethos of care for every human being. (Seidelman, 1996)

The Psychiatrist's Perspective

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President, Canadian Academy of Geriatric Psychiatry
Co-chair, Canadian Coalition for Seniors Mental Health

It is important that Survivors of the Holocaust are always seen as individuals who have shown the capacity for strength and survival. For those of us working in the field of psychiatry, there is a tendency to recall particular patients whom we have cared for. As a result, we often end up with a somewhat skewed or biased image of Holocaust Survivors as a group. It is important to emphasize that the majority of Holocaust Survivors managed to cope remarkably well with the extreme traumas that they experienced during World War II. Cohen (1991) states that, "focusing on aging Survivors only as damaged individuals further adds to their sense of humiliation and shame." That being said, it is important to be aware of certain groups of symptoms that have been described in some Holocaust Survivors.

Literature Review

Niederland (1961), who probably coined the term "Survivor syndrome," stressed the severity of this group of symptoms. He noted chronic depressive states as well as a tendency to isolation and withdrawal, with a high incidence of psychosis and alterations of personality, identity, body image and self-image. He also noted psychosomatic conditions and "Survivor guilt."

Chodoff (1963) similarly described chronic depression, chronic anxiety, personality changes, guilt, isolation of affect, memory disturbances and avoidance of psychiatric help. Henry Krystal (1968) in his remarkable book Massive Psychic Trauma studied 149 random case records of Survivors and reported that 79 percent of these Survivors had chronic depressive manifestations. On the other hand, Sigal and Weinfeld (1989) noted that, in spite of the obvious harmful effects of the Holocaust, "we are struck more by the variability in the Survivors' experiences and in the general degree to which they, and certainly their children, have overcome the traumas of the past."

Solkoff (1982) criticized the existing literature noting that the methodological and experimental approaches were seriously flawed. He emphasized that Survivor samples are usually biased - that is, they are often based on psychiatric populations or individuals seeking reparations, and researchers tended to use unreliable methods in assessing psychopathology.

Post-traumatic Stress Disorder and Depression in Holocaust Survivors

Using the current diagnostic system of mental disorders (the Diagnostic and Statistical Manual of the American Psychiatric Association, known as DSM-IV), it would appear that some Survivors have suffered from post-traumatic stress disorder (PTSD). Others show signs of mood disorders including dysthymic disorder (chronic depression), anxiety disorders and long-standing adjustment disorders. The earlier literature, which grouped Survivors into a single syndrome, called attention to the suffering of these individuals. In doing so, they may have been helpful during the complex process of trying to obtain compensation from the German government.

A diagnosis of post-traumatic stress disorder or PTSD requires a number of criteria. First, the person must have been exposed to a traumatic event in which both of the following were present:

"The person experienced, witnessed or was confronted with an event or events, that involved actual or threatened death or serious injury or a threat to the physical integrity of self, or others, and the person's response involved intense fear, helplessness or horror."

Secondly, the traumatic event is persistently re-experienced in one or more of the following ways:

"Recurrent and intrusive distressing recollections or dreams, acting or feeling as if the traumatic event were recurring, intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event, and physiological reactivity on exposure to these cues."

In addition, there should be persistent avoidance of stimuli associated with the trauma, numbing of general responsiveness, as well as persistent symptoms of increased arousal, such as difficulty falling or staying asleep, irritability or outbursts of anger, difficulty concentrating, hyper-vigilance or an exaggerated startle response.

Many Holocaust Survivors describe having some of these symptoms dating back to the War itself. It is important to note that if one does not ask specifically about these symptoms, they are often not spontaneously reported by the patient. It is not unusual to see individuals who have a history of PTSD and, in addition, have other psychiatric problems, such as an episode of severe depression or long-standing chronic depression (dysthymic disorder).

Healthcare professionals should recognize the typical symptoms of a major (clinical) depression. These include sleep disturbances, lack of energy and interest, feelings of guilt, feelings of helplessness and hopelessness, poor concentration, appetite changes, agitation or apathy and suicidal ideation. It is interesting to note that in a recent study at a Day Hospital, the profile of depression in Holocaust Survivors was not significantly different from non-Holocaust Survivors (Conn, et al. 2000). It was also particularly gratifying to discover that the prognosis for recovery from depression was just as likely among the depressed Holocaust Survivors as among depressed non-Survivor patients attending the program.

It is worth noting that certain symptoms are often prominent in depressed Holocaust Survivors. These include severe sleep disturbance, an inability to experience any pleasure (anhedonia) and an inability to describe feelings (alexithymia). Henry Krystal also describes a sense of shame, feelings of guilt relating to survival, difficulties controlling anger and an excessive use of certain psychological defense mechanisms such as repression or denial. Dr. Krystal also makes note of several important issues:

Being forced to remember may be extremely traumatic and painful for Survivors of the Holocaust, many of whom have spent much of their lives "fighting off their memories."

For some individuals it may be important to continue to feel a sense of rage as part of bearing witness to the events of the Holocaust

Effective grieving and mourning has been extremely difficult and this may have limited an individual's capacity for "integration."

Severe depression often responds well to a combination of antidepressant medication and psychotherapy. Various forms of psychotherapy can be of help, including cognitive-behavioural therapy (CBT), psychodynamically-oriented psychotherapy, interpersonal psychotherapy (IPT) and supportive psychotherapy.

Patients with chronic insomnia are often treated with long-term tranquillizers such as lorazepam (Ativan) or temazepam (Restoril). It is generally recommended that these medications be used for limited periods of time as the person may become tolerant to a particular dosage and thus require increasing amounts of the drug to experience benefit. Nevertheless, some individuals do seem to subjectively report ongoing benefits even from a low dosage. Certain tranquillizers that tend to accumulate in the body, such as diazepam (Valium) are generally not recommended for use in the elderly.

Patients with PTSD symptoms may also benefit from the psychotherapies. Holocaust Survivors may vary greatly in their capacity to explore memories and images from the War. Various medications - most commonly antidepressants -- are also used to treat PTSD. Recent studies have also examined the benefits of neuroleptic and anticonvulsant medications, with some reports of success.

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Psychiatric Evaluation of Survivors

During the initial clinical interview of a psychiatric evaluation, it is normal to take a full personal history which includes questions relating to an individual's early life, childhood, relationships with parents, siblings and friends, school experiences, sexual development, etc. For some Holocaust Survivors, talking about their early lives can be extremely painful. For some individuals, reflecting on their childhoods is difficult because that part of their lives was destroyed.

Questions about how an individual experienced and survived the Holocaust should be carefully phrased in an open-ended fashion. It is important that the clinician be sensitive to an individual's difficulty describing the traumatic and horrific events that they may have experienced. There is a continuum, ranging from a complete inability to describe these experiences to openness and, indeed, to a desire to share details of the past. For some people it may take several sessions before enough trust has developed that they are able to share such information, as well as their associated emotions. It is also important to be aware of one's personal responses and reactions when asking about these experiences. Because it is also painful for us to hear about these horrific events, there may be a reluctance to ask the type of questions that will encourage the Survivor to open up.

Survivors with Dementia

Detailed cognitive testing of a Holocaust Survivor with dementia must be carried out in a sensitive manner. An excessive bombardment of questions presented in a cold or regimented fashion can be highly threatening. This comment applies to all individuals with cognitive impairment, but it is important to be aware that Holocaust Survivors may be particularly sensitive. It is also important to note that, as an individual develops dementia, in most cases he or she will progressively lose short-term (recent) memory. As a result, the person may spend more time focusing on memories from the distant past. In some circumstances this will lead to a focus on painful traumas. The person may have difficulty separating current reality from past memories. In some circumstances this can lead to paranoid thoughts or delusions relating to the current environment.

Working with Survivors who have Dementia

Individuals with dementia may present a variety of challenges to caregivers. These include memory and functional difficulties, mood changes, delusions and hallucinations and behavioural issues such as agitation and aggression. It is important for staff to take a comprehensive biopsychosocial approach to these problems. Creating a relaxing, non-stressful physical environment - one with minimal noise and stimulation - can be helpful. Taking a behavioural approach can be useful in managing the patient's agitation and aggression; this involves carefully evaluating behavioural triggers and monitoring the caregivers' responses. If a person is disoriented and appears to be re-living past traumas, it is important to gently re-orient and reassure the patient without openly challenging the legitimacy of what his or her subjective experiences.

Medications may play a positive role in some situations - for example, in controlling severe and persisting depression, disturbing psychotic symptoms and severe agitation. Excessive institutional regimentation should be avoided as this can be a trigger for memories of previous incarceration. Wherever possible the person should be offered a maximum level of autonomy that is practical, yet which provides an optimum level of safety.

The Nurse’s Perspective

Anna Grinberg RN BScN, Marilyn Rodgers RN, CRRN, GNC(C), Laurie Bernick RN MScN ACNP GNC(C), Lucie Holynaty RN GNC(C), Baycrest Centre

Nurses may meet older Survivors in both community and in health care settings. The nurse is concerned with the human responses of an individual, a family or a group in the context of health and illness. The goal is that care and healing will occur. The primary role of the nurse is to support the person, family, or group with their physical, psychosocial, behavioural and personal care needs. The nurse often is the coordinator of care and should also be a strong advocate for the individual and his/her family.

Holocaust Survivors may have been exposed to nurses who assisted during human medical experimentation during the War and retain certain negative associations. In general , many Survivors feel very vulnerable discussing their health concerns, and nurses must be aware and sensitive to their issues.

Nursing Issues Raised in Case Study:

- challenges of providing personal care
- difficulty teaching client due to poor insight and cognitive challenges
- difficulty working with the family around their expectations for prognosis and progress
- communication with the family and the provision of family-centered care
- building a trusting relationship; lack of trust
- dealing with verbal and physical abuse by family and client
- communication of care needs
- guiding family in making difficult care related decisions
- impact of the environment on the caring situation (e.g. the concentration camp's closed-in environment being transferred to the hospital experience)
- safety of client and staff, risks to client and staff
- pain and suffering
- respecting client's wishes and personal preferences
- dealing with feelings of loss from all aspects (physical and personal loss; loss of cognitive abilities, loss of relationships within the family; loss of roles)
- dealing with feelings of poor self-esteem and powerlessness
- second generation children of Holocaust Survivors may experience feelings of guilt, fear and a need to be a strong advocate
- impact of very high demands from family on nursing staff

The Nursing Interventions: Comprehensive Care

It is essential for nurses to be sensitive and resourceful in providing personal care to Holocaust Survivors, since there are many potential triggers in the hospital/long term care setting. There are many experiences during the course of each day that could provoke a negative response, especially when care is being provided. The nature of the care - toileting, bathing, grooming - is very private and often involves touch. From clinical experience, it is evident that how care is provided can have a huge impact on the outcome for both nurse and client.

During the course of treatment and preventive care, the nurse may be required to wake patients in the middle of the night to reposition them and to provide pericare. Nurses often discuss sensitive issues around patients' care needs and wishes, and also deal regularly with family, sometimes during a health-related or other crisis. Each of these situations requires great sensitivity on the part of nursing staff.

In Mrs. A.s' case, certain events or situations seemed to trigger a negative response when she was at the Day Care program. For example, because she associated riding the bus with the transport train to the concentration camps, staff explored other means of transportation to and from the program Rather than taking the bus with the other participants, Mrs. A. traveled to the program by taxi, accompanied by a caregiver.

Mrs. A. often refused to remove her coat when she arrived at the program. She associated the removal of her coat with not being able to go home, and also feared that her coat would be stolen. She may have been responding to painful memories of being stripped of all her personal belongings when she arrived at the concentration camp. It was decided that Mrs. A. could remain dressed and would take off her coat if and when she felt comfortable doing so

Mrs. A. was often suspicious when she met new people and also when accepting food from strangers. Staff tried to allay these fears by having the same person serve her meals at each sitting. She was also given a variety of food choices. Over time, this allowed Mrs. A. to begin trusting her care providers.

Some Survivors may be easily upset by certain specific types of music, accents, and apparel which trigger memories of previous trauma and loss. In Mrs. A.'s case, her family told staff that she enjoyed Yiddish music and songs. Staff caring for her did not dress in uniforms and did not have strong accents.

Mrs. A. was very anxious when given a shower. Survivors may associate a shower or other personal care with experiences in a concentration camp. Jews were often gathered in the shower room under false pretenses before being gassed to death. To build familiarity and a sense of trust, it was arranged for the same care provider to help Mrs. A. when she showered. An effort was made to deliver personal care Mrs. A. was not sleepy or restless.

Mrs. A. was also prone to constipation. For a person who is cognitively impaired, constipation is especially difficult - it causes chronic physical discomfort that cannot be explained in the person's own mind. In combination with other preventative strategies (e.g. special diet, fluids), staff made sure Mrs. A. used the commode after breakfast daily. After she was transferred to an in-patient floor, she received a "bracelet" that would alert staff when was leaving the area. This bracelet, normally an institutional-looking device, was specially designed for Mrs. A. to resemble jewellery, which she was more willing to wear.

Mrs. A was relocated to various programs as her medical needs became more complex. Institutionalization often causes additional emotional and psychological trauma for the aging Survivor. Confined to the Day Care program's locked unit reminded Mrs. A of being confined to the ghetto and of people being locked up in the concentration camps. To allay her fears, Mrs. A. was allowed to move freely within the Day Care unit. Because of her potential difficulties with confinement, arrangements were also made to allow her to walk outside and to leave the unit while accompanied by a relative, personal companion, volunteer or staff member. Once trust was established, Mrs. A. became much more flexible with her routines.

Establishing a Supportive Plan of Care

Some Survivors who are cognitively impaired go through periods of distressing dreams and may experience hallucinations and/or delusions. They may experience outbursts of anger, crying, screaming and extreme fearfulness. To reduce the possibility of harm to themselves and others, environmental modifications may be needed.

For example, Mrs. A. could have had the potential to harm herself, so all sharp objects were removed from her room. The family hired a personal companion who spoke Yiddish, Mrs. A.'s language of origin, and with time, a trusting relationship was established.

Together, the family, care team and personal companion developed a plan with Mrs. A. Education was provided as needed, and efforts were made to build consistency of care - the same regular registered nurse cared for Mrs. A. whenever possible. The family received regular telephone calls from the nurse concerning any changes. This kept the lines of communication open, which helped the family's frustration and pain over their mother's illness.

The nurse manager on the unit played a pivotal role in establishing this supportive care plan and trusting relationship with the family. She made herself available and accessible to the family. Besides reducing the family's anxiety, this reassured them that their concerns would be addressed. This allowed them to became active partners in their mother's care.

Institutional Care vs. Community Care

Nurses need to understand the family's role as advocates for a member who is a Survivor. The nursing team may feel helpless and angry with the family for being suspicious and having unrealistic expectations of them. The nursing team needs to constantly clarify the care plan with the family. Opportunities to meet with the family and to listen to their care needs are critical.

In many families of Holocaust Survivors, issues related to medical care and medical directives are very sensitive. During the War, people experienced many losses and were not able to grieve normally. In Mrs. A.'s situation, for example, the family felt that the medical/nursing staff were not doing enough for their mother. They also insisted that her needs be met in an "urgent" manner. Numerous family meetings were held on a regular basis to allow the family to address their concerns and to have ongoing input to their mother's care. The many decisions they needed to make on behalf of their mother were discussed and shared with the staff.

Tips for Nurses

Trust. Nurses must find ways to build trust, to increase their own knowledge, to advocate and to address issues of caregiver burden.

Listen to the person. It is important for nurses to listen to their patients and hear their wishes before decisions are made. A small adjustment to how or when a particular task is performed might go a long way in providing more sensitive care to a Survivor.

Treat every individual in a personal and unique way. Nurses should not label people for their ways or how they respond to their situation. Nurses should confront other staff who say: "She's not my patient" or "She's a difficult patient".

Investment of time of staff. Nurse managers need to understand that it often takes more time to perform a particular task with a Survivor.

Build in consistency and routines. Understand previous life experiences that are meaningful for the person, and find the time to listen to the Survivors' stories. Use appropriate cueing to orient the person to his or her environment and daily routine (e.g. clock, calendar, access to a window that allows them to see the weather outside and notice time of day). Although structure is helpful for many older people, especially for those with cognitive challenges, be aware that extreme, enforced schedules were a fact of life during the Holocaust - for example, train schedules that were used to transport Jews to the camps.

Provide a supportive environment. Create a calming environment by surrounding the person with meaningful, familiar objects such as photographs. In designing and maintaining personal and common spaces, colours and art can help reduce the sterile "institutionalized" feel so common in long-term care settings. Be aware of the potential impact nursing uniforms may have on the Holocaust Survivor. For example, lab jackets, masks, gloves, could be associated with medical experimentation

Increase everyone's knowledge and sensitivity through training. In order to be effective this must be ongoing. Educational programs should be constantly developed and build on people's existing skills.

Communicate with all family members. Take the time to meet everyone. In Mrs. A.'s case, family and staff met every week to discuss her progress and any changes to the care plan. Provide ongoing education to family members around the impact of the person's cognitive and/or functional losses. Mrs. A.'s family had difficulty accepting her physical and cognitive losses. They required ongoing discussions and education to help them understand both her disabilities and her remaining capabilities. Respecting the family's readiness to learn is important. The family's frustrations need to be acknowledged. Always provide meaningful and genuine caring interaction with the family

Have one main contact person on the team. In difficult cases like Mrs. A.'s, it may be helpful to refer the family to one contact person. However, it's important that information about the client and family is shared with other team members.

Know the person's background. If a patient is Holocaust Survivor, staff must know something about their early experiences. This can help predict triggers for negative emotions and behaviours. Understanding who the Holocaust Survivor is encourages awareness. Such awareness helps the care team better understand how the client might react when he or she enters a hospital or long-term care facility.

Remember that not all problems or concerns can be resolved - but there is always room for compromise.

Assess for triggers that can contribute to behavioural responses. A comprehensive assessment is critical in order to avoid misinterpretation of behaviour and to provide the necessary care. Look for cues regarding the person's response to his or her situation. For example, at one point in her hospital stay, Mrs. A. stopped eating. A referral to the dentist was made and with treatment, her appetite improved. Her refusal to eat could easily have been misinterpreted if a thorough assessment had not been made. Assess for critical areas might be contributing to painful memories. The presence of pain, delusions, hallucinations, delirium, physical illness, a sense of confinement, side effects of medications and misinterpretation of environmental cues all have the potential to impact the person's responses.

Install a sense of worth. Incorporate pleasurable activities in the person's daily care. Mrs. A. enjoyed her tea and snacking on food. A volunteer spent time with Mrs. A. off the unit in order to provide her with some diversion and an opportunity for social interactions. These activities helped to provide her with a feeling of self worth. Provide the person with an activity that makes him/her feel useful (e.g watering the flowers daily, doing laundry with the caregiver). Ensure the person is well-groomed and clean, is wearing appropriately sized clothes and is NOT dressed in a hospital gown or night-time clothes unless this is necessary. Be aware of the importance of body image. Ensure that patients have their dentures, glasses and walking devices; encourage them to wear make-up and jewelry if this is important to them; make sure that nails are cared for and that facial hair is kept groomed.

Many alternative strategies can be used to avoid confining a person to a chair or bed. For example, use low beds and appropriate supportive seating. Eliminate the use of restraints. If the person is at risk of harming him/herself or another person, seek consultation from other health professionals about how to solve these challenging behaviours in order to prevent injury.

Providing Personal Care. Continuity of care is key in order to establish trusting relationships. It also ensures staff's ability to recognize and control the impact of positive/negative triggers. Consistency in the approach to care is also important - for example, incorporating the individual's preferences, wishes and desired routines. There are many reasons personal care might trigger negative memories. For example showers might be associated with gas chambers. In such cases, provide a tub or bed bath or have the person wash at the sink, using non-rinse products

Use a variety of mediums to calm and personalize care. For example, it can help to play meaningful music (including songs sung in a familiar language) during morning care. Use a soft touch, a soft, low voice, soothing lighting or aromatherapy. For example, Mrs. A. enjoyed having Yiddish songs play during personal care periods. If a particular staff member or volunteer somehow triggers a memory of the Holocaust, this should not be taken personally. If possible, another person should be brought in to provide the care. Female Survivors sometimes react with fear when a male person delivers some type of care or service. Other Survivors may be sensitive when care providers speak with a foreign accent or in a high-pitched voiced.

Use the person's assistive devices to maximize understanding. For example, hearing aid, glasses, dentures, personal augmented devices, and translators should be used, not forgotten in a drawer. Be aware of sensory neglect, hearing loss and visual impairment during care and when approaching the person.

Commit to the care plan but be flexible. Be adaptable wherever possible. Do not impose rules such as "bowel days" or "bed days." As much as possible, respect the person's familiar routines. The care plan can be a shared responsibility with the client's family, and it should be adapted and modified as the care needs change.

Above all, RESPECT the person as an individual. Respect the person's wishes, protect their privacy, and try to ensure their dignity when you are providing care.

The Chaplain's Perspective

Rabbi Dr. Norman Berlat, Director of Pastoral Care, Baycrest Centre
Rabbi Ronald Weiss, Director of Chaplaincy Services, Jewish Family and Child Services

A Chaplain is a clergyperson who has engaged in extensive training beyond ordination and who has been certified as a professional pastoral care provider by national or international chaplaincy organizations. He or she might work with older Survivors in the community and within the long-term care setting. The primary roles of the chaplain are to provide comfort as needed, to either the Survivor or to family members, and to help them cope with their spirituality and related life issues.

As patients and clients, Survivors present unique and unusual pastoral care concerns. The chaplain must be aware that while some Survivors respond to spiritual guidance, others may no longer believe in God. They may not recognize the need for religion or feel that religion has a role in their lives after their horrific experiences.

The Holocaust spans 12 years that have no parallel for evil in the history of mankind. Millions of people, six million of them Jews, were singled out for extermination because of their religious beliefs, cultural heritage or ethnic origin. Nazi tormentors considered them untermentchen (subhuman beings) and treated them without any semblance of dignity or appropriate amenities.

The victims were subjected to conflicting messages. The entrance to Auschwitz bore a sign "Arbeit Macht Frei" which translates to "Work Makes (for) Freedom." The Holocaust experience demonstrated the intentional incongruity of this reality. Release from horrendous suffering came about through death. It was this planned and purposeful conflictual experience that was a factor in the dehumanization of masses of persons.

Following liberation and subsequent attempts at rebuilding their lives, the Survivors continued to grapple with the life long effects of their horrific War-time experiences. These difficulties are often exacerbated, and may posse specific challenges, as Holocaust Survivors reach the end stage of life.

Coping with Death and Dying

Many Survivors have manifested great difficulty coming to terms with the reality of their impending death. After having lived through the shadow of death for many years, they are often unwilling to believe that they are now close to death themselves.

The physician, who requested the chaplain's involvement in the case of Mrs. J. and her seriously ill son, felt medical science had very little to offer the man and his mother. The chaplain and the doctor discussed the function of the art of medicine. In this context both patient and parent could be treated and cared for. The patient was admitted to the hospital, appropriate medical orders were issued, and the physician visited daily. He ordered pain medications and fluid to prevent dehydration. But more than this, he offered himself and presented an image of caring to the family constellation. Mrs. J.'s son succumbed to his illness two weeks following admission.

The mother genuinely felt that her efforts were purposeful in providing all that she could for her son. She was able to return home with his remains knowing that no stone had been left unturned. It was this caring attitude that enabled her to confront the reality of his death with the seeds of comfort already sown. In our current fiscal climate, this hospital admission might be deemed inappropriate. However, the caring, concern and compassion shown to the family was an appropriate response.

Strained Relations

Survivor parents may have particularly difficult relationships with their children. These children are frequently sheltered, and sometimes smothered, by their zealously cautious parents. It is easy to understand how parents, after having lost everything once before, become overprotective in order to guard against possible future loss. It is equally easy to understand how children, even those who understand their parents' fears, would rebel against such intrusive and controlling behaviour.

Similarly, sometimes the horrific experiences of Holocaust Survivors can render them unable to communicate effectively, even with those they love most. When a person in either of these situations is dying, these issues can become major obstacles to necessary closure. Everyone involved is in desperate need to reconcile, but the strained relationships, entrenched over many years, combined with anxiety over the current illness, often make the principals unable to obtain resolution.

The chaplain can be helpful in the role of facilitator, assisting each family member see the perspective of the other. People in a traumatic situation often become locked in their own analysis of a situation. They are unable to experience the larger picture of family dynamics and concerns. The chaplain who is a trained counsellor is often able to help parties move towards greater mutual understanding. This understanding is a significant factor in bringing the parties together and opening the possibility of more fruitful and healthy inter-family discussions.

For example, when one chaplain was introduced to a terminally ill Holocaust Survivor, the patient said, "I know I'm dying, but don't tell my wife". Later, when the chaplain was speaking privately to the wife, she confided, "I know my husband is dying, but he doesn't know, and I don't want you to tell him".

Spouses felt the other had enough pain in their lives and wanted to spare the other additional grief. For years they lived surrounded by death. Now, in order to protect their loved one, they wanted to keep death as far away as possible, for as long as possible. Yet by pursuing such a path, not only was resolution and any possibility of closure forestalled, the precious time they still had together was not being used to maximum potential.

In such a situation, the chaplain might speak to each spouse separately and emphasize that they have shared many life issues together. The chaplain could emphasize that it would be therapeutic for the couple the face their current situation together. Otherwise, the inevitable loss face individually and collectively will be magnified. By approaching each person in this way, the chaplain can contribute to a broadening of perspective and possibly to the opening of meaningful dialogue.

Impact of Urgent Illness

During the selection process at the concentration camp or during the lengthy roll calls, those who appeared sick might pinch their cheeks or spread blood on them to demonstrate an appearance of health. For those who were unhealthy, or appeared so, their destination was the gas chamber and the crematorium.

Thus a response to urgent illness such as a heart attack or aggressive cancer might be denial, delayed request for medical care, or request for immediate care so that homeostasis might be restored. Elderly Survivors require assurance that they are in a safe environment and will be cared for and treated with dignity should an acute illness arise. Such communication requires sensitive honesty and integrity, always keeping in mind the clients' Holocaust experience.

Impact of Chronic Illness

Aging Survivors experience complex heath care needs and requirements. Some must relinquish their home environment and enter an institutional care settings. This may remind them of how they were once uprooted from secure homes and relocated to the death camps. Adjustment to the new environment may be traumatic and elicit painful memories.

Losses are associated with normal aging. These losses are exaggerated for the Holocaust Survivor as friends and family pass on. This experience may cause them to re-live earlier traumatic events that occurred during the Holocaust. Chronic illness itself may mimic situations that transpired many decades earlier when the elderly and people who were deemed ill or weak were immediately sent to their deaths.

It is important for the chaplain to approach such clients and reassure them that they will be cared for. Orientation to reality and personal safety are essential. Otherwise the horrific experiences encountered during the Holocaust may be felt as current reality.

Impact of Long-Term Care

A human being experiences homeostasis and security in their own home. Eventually, their life circumstances may require relocation to an institutional environment. No matter how supportive or home-like the institution may be, persons may experience one or more of the following:

- isolation from family, friends and community
- isolation from familiar houses of worship
- isolation from meaningful social groups
- loss of autonomy
- loss of control, perhaps over one's most private and personal needs
- the effects of dementing illness

Many Holocaust Survivors experienced similar losses during their period of internment. Moving to and living within the institution may cause them to re-focus on these earlier memories.

Theological Issues

"Where was God then?" "Where is God now?" These questions represent a familiar and often angry response of Holocaust Survivors at the end of their lives. How is this to be handled? What is the appropriate response? In one case, the chaplain approached an elderly gentleman and asked if he would join in a minyan (prayer service) for someone who was observing a Yahrtzeit (anniversary of a loved one's death). He remarked, "NO! YOUR God died along with people in the concentration camps. There is no one to speak to. Why should I come?"

It is significant to accept the individual's anger directed at God. The chaplain does not become reactive to defend God. The Survivor is yet awakening from the emotional anesthesia that has enabled him to survive. He or she once again experiences the pain of the ultimate issues directed to the Ultimate One. Only the sufferer can discover an acceptable answer to loss. Sharing the intensity of pain with the non-judgmental chaplain can help reconnect the Survivor with his faith group.

Language of the Survivors

Survivors often use terminology that has particular meaning for them. One patient, to the great discomfort of staff, would refer to any medical procedure as an "experiment." This patient had undergone cruel experimentation in the camps and, now psychologically and emotionally wounded, associated all medical care with "experimentation".

It was helpful to have the chaplain orient staff about certain terminology common to Holocaust Survivors. This helped reassure them that such expressions did not reflect any value judgment on the quality of their care. Another patient, an elderly lady, refused a life-saving pacemaker because it involved a minor surgical procedure. She had been surgically damaged during the Holocaust and when this procedure was proposed, she said, "No cut. God who wanted me to live until now, will let me live if He so wants, but no cut."

The sensitive chaplain may offer such a patient the chance to share her fears, and also remain with her while the physician explains the nature of the procedure. It has been useful and supportive to Holocaust Survivors and their families to have a chaplain with them during certain medical or surgical procedures. This creates a genuine aura of trust with a co-religionist who represents assurance that nothing will be done that is not within the parameters of mutually agreed care.

Conclusion

Survivors present with dynamics that are unparalleled in medical practice. The need for sensitive and compassionate care is essential. The trained chaplain collaborates with medical personnel in effectively treating the whole patient and the family unit. This is vital, since spiritual and psychological needs impact on a patient's well-being and affect the quality of life.

Healing does not necessarily result in obtaining a cure. But it does reconcile the spirituous-emotional factors that enable a person to continue living despite the reality they are forced to confront. Healing can be achieved through caring and reconciliation.

It was the hope that lies embedded deep in the hearts of the Survivors that enabled them to endure the endurable and to rebuild their lives.

Tips for the Chaplain

- Listen. Be sensitive about what is being said, what is being withheld and what is truly meant.
- Be aware of the unique study of "Holocaust Theology" in order to be sensitive to the wide range of Survivors' responses to their post-Holocaust religious observance.
- Be gracious with your time in ministering to Holocaust Survivors and their families.
- Demonstrate genuine empathy.
- Learn about the nature of the Holocaust and its impact upon people.
- Understand your personal feelings and responses in ministering to this sensitive group of people.

- Provide pastoral support for the client, their family members, and also to the staff who care for them.
- Be aware of triggers which might set off flashbacks, and learn how to respond pastorally to your clients.
- Recognize the Survivor's resilience in maintaining a spiritual identity post- Holocaust.
- Remember that you stand upon sacred ground in ministering to those who endured the unendurable and survived.

The Food and Nutrition Services Perspective

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Proving food and nutrition services involves both the Clinical Dietitian and the Dietary Aide/Server. The Clinical Dietitian tends to work with older Survivors both in the community and also within the hospital or nursing home setting. The Dietary Aide/Server or Food Service Worker usually works with older Survivors in the long-term care setting.

The primary roles of the Clinical Dietitian are to conduct nutritional assessment, to provide care around food and nutrition and to offer counseling to the aging Survivor and family members. The goal of such counseling is to develop useful strategies and make informed decisions towards achieving the best possible nutritional status and overall enjoyment of the mealtime experience.

The primary role of the Dietary Aide/Server is to facilitate food choice within the context of therapeutic guidelines and to maintain a gentle, pleasant, caring and reassuring demeanor while serving food in a dining room setting. The goal is to promote good food intake and to provide the best possible mealtime atmosphere and experience for the client.

Both the Clinical Dietitian and the Dietary Aide/Server must be aware that aging Survivors and their families may experience a wide variety of reactions and responses related to food. These include issues surrounding food security (having enough to eat), the activity of eating, and the emotional and psychological meanings of food. Food-related "triggers" may provoke disturbing symptoms among older Survivors and their families. Feelings that have remained latent for years following the extreme trauma of their Holocaust experience may emerge now.

It is sometimes difficult to determine the specific etiology of symptoms derived from the complex interaction of factors related to coping with chronic and acute illness, cognitive and physical impairment, the impact of institutionalization and the loss of control in day-to-day activities. Aging Survivors and their families must cope with aging, death and dying which are permeated with the legacy of the Holocaust. In some cases, these events may be remembered as a horrific past event. In others, particularly where dementia has destroyed short-term memory, the past intrudes painfully as current reality.

Impact of Chronic Illness

As Survivors age, it becomes increasingly likely that a variety of therapeutic diet interventions may be required to address various chronic progressive diseases and conditions.

These interventions may be related to swallowing problems or progressive chewing difficulty (requiring texture modified and/or thickened foods), food restrictions related to the need to control diabetes (restriction of juices, Â✥ portions of desserts, use of sugar substitute) and sodium restriction (restriction of smoked and pickled foods, including favourites such as lox or herring). Such health-related dietary changes can be difficult for most aging individuals. But for those who survived the Holocaust, reaction to such restrictions - sometimes perceived as deprivation or punishment - may be extreme.

Age-related impairments in the ability to smell and to taste sweet and salty foods, and the increased sensitivity to bitter and tart flavour components can distort taste perception. This may cause an older person to become angry, causing comments such as: "Food used to taste good.

What have they done to the food? How have they cooked the food to make it taste bad".

Mrs. E., for example, has difficulty chewing, and some of her medications cause dry mouth, further distorting her ability to taste her food. She suffers from a "bad stomach," chronic indigestion that may be related to her inability to chew food to a soft enough texture before she swallows it. She blames this on the food and resists suggestions that softer/minced textures might be better for her. She is worried that the "other food" might be an echo of her past and not like real food. Both the dietitian and the server need to be sensitive to this concern and present the altered textured food for her to try on a gradual basis, making every effort to have it appear as much like regular food as possible.

All restrictions and changes can be viewed as more seriously impacting on the quality of life of the Survivor, evoking a renewed sense of deprivation and feelings of forced regimentation. The dietitian and other members of the health care team may be required to mediate disputes between the Survivor and family members. Such discussions often revolve around with differing ideas on what is most important to the individual at this time of life, versus what might be the best choice from a purely therapeutic perspective. Quality of life, and the right of the Survivor to make choices whenever possible needs to be protected.

For Survivors with Alzheimer's Disease (and accompanying short-term memory loss), the inability to recall treasured recipes that were central to holiday celebrations and special family times can be very painful and frustrating.

Impact of Acute Illness and Hospitalization

Hospitalization brings yet another relocation, with accompanying drastic changes in routine and schedule related to food and other issues connected to daily living.

From a nutritional point of view, acute illness may require invasive therapeutic interventions such as hypodermoclysis (an injection of fluid under the skin to provide hydration) or tube feeding, on a short- or long-term basis.

For aging Survivors who were subjected to medical experimentation, undergoing such clinical procedures in an acute care setting may evoke horrifying memories of past trauma. Some family members of Survivors may not want to see their loved one suffer even more after having suffered so much in the past, and so may reject the more invasive procedure. Other family members may want everything to be done so that their parent does not "starve again". Sometimes there may be serious conflict among family members on this issue. In some cases, an adult child may insist on interventions that were contraindicated in the "living will" of the Survivor. These conflicts and issues require consultation with the entire health care team so that the Survivor and family will feel supported in making the decisions about nutritional care that are most in keeping with their personal values and beliefs.

Impact on Family

Coping with a diagnosis of Alzheimer's Disease and making the decision to place a loved one in a care facility is traumatic and painful for all families. This is especially so for Survivor families who are profoundly motivated to protect the Survivor from further suffering. The adjustment to the relocation is enormous, and family members need support and understanding, especially during the period immediately after admission.

Food often becomes a special focus during the adjustment period. In the case of Mrs. E., her daughter is primarily responsible for making decisions, mainly because the long-term care facility is located in the city where she lives. Mrs. E.'s son lives far away and struggles with his inability to be as involved with care decisions, as he would like to be. He sometimes overcompensates for his inability to visit more often. In an effort to make a real difference when he does see his mother, he often insists on changes that conflict with care decisions previously made by Mrs. E. and her daughter in consultation with the care team.

Family Involvement and Communications

Food was always of key importance in Mrs. E.'s family. As the traditional wife and mother, she was very involved in shopping for food as well as cooking and serving meals, and tends to focus her adjustment issues on whether her meals have been prepared and served "her way." Sometimes her children disagree on what foods their mother should be served, along with many other day-to-day care concerns.

Both Mrs. E.'s children need factual, concrete and practical information and reassurance so they can form a picture of their mother's day today routine. Keeping them up to date about Mrs. E's intake via a food diary and by reviewing Mrs. E.'s weight record is useful in reducing stress and disagreements. It is helpful for them to hear from Mrs. E.'s food server about their mother's concerns over one day's lunch, but also her enjoyment of one day's supper. Survivor families need to know that the dietitians, serving staff and department administrative staff are sensitive to and informed about their mother's special needs as a Holocaust Survivor.

Families are often able to pass along valuable information that the Survivor may not be able to provide. The dietitian and the server need must listen to family members, and learn about any food-related concerns and behaviours prior to admission. This will allow staff to become proactive in helping Survivors and family members make a gradual and positive adjustment to life in the facility. It's usually helpful for family members to know about daily food choices prior to admission, and also be told what to expect during holidays. They should be informed that the client's food preferences will guide menu development within available resources. Family members and staff should make every effort to honour decisions about food that an elderly Survivor is still able to make.

Staff Coping with Emotional Impact of Caring for Survivors and the Potential for Burnout

It is important and also challenging to hear and comprehend the enormity of the Survivor's losses. We are often astonished at the fortitude of such people, as they picked up the pieces of their shattered reality and created meaning. As with other care providers, dietitians and food servers may need support in order to continue providing competent clinical care and service. Education about the Holocaust can help them better understand and cope with the rage that sometimes surfaces during a routine intervention or provision of service.

Staff is often confronted with difficult situations. A helpful suggestion - for example, recommending that the person's meal time be changed, that texture-altered food might be easier for them to swallow and thus improve nutritional status, mentioning the need to forgo a favourite food at a certain time in recognition of a special holiday or in keeping with the Jewish dietary laws of Kashruth - can trigger an extreme emotional reaction. When these reactions result in verbal abuse or physically aggressive behaviours, food service staff need emotional support. Such support may draw on the resources of the entire care team, as well as colleagues. The goal is to continue providing responsive and sensitive care to the Holocaust Survivor and the Survivor family.

Institutional Care vs. Community Care

A dietitian working with Survivors and Survivor families in a community setting must have the same degree of knowledge and support as colleagues in a care facility.

In the community, many of the same kinds of characteristics manifest themselves. Food hoarding in the home is common - the dietitian may observe huge quantities of aging canned goods on storage shelves or a freezer full of food of indeterminate age.

Survivors who still live at home display many of the same food security and safety issues as those in institutional care - for example, the need to see plenty of food available and the extreme fear of food waste. Where food access and safety issues might place the Survivor at risk, the dietitian needs to be informed about where and how to put the appropriate referrals in place.

Tips for Dietitians in Institutional Settings

Listen to food concerns. It's also important to provide objective and concrete information to reassure the Survivor and family members that nutritional status is being maintained and mealtime observation is ongoing. Sharing of weight records and intake records are helpful and constructive, providing objective measures which can assist with the adjustment period and help determine where intervention is needed.

Assist the Survivor to maintain autonomy in choice and timing of meals and snacks. Consult with the health care team to plan for appropriate levels of assistance with eating at the right time of day. This will help the Survivor participate in his or her care and may reduce excess disability.

Use texture-altered food creatively. Try to make minced and pureed products look and taste and much like regular food as possible. The foods may then be more recognizable, which may lead to greater acceptance of these items, enjoyment of meals, and better nutritional intake.

Be sensitive to and tolerant of unusual food behaviours. For example, some Survivors may exhibit exaggerated behaviours - for example, hoarding food, hiding and protecting food, giving gifts of food, excessive or opportunistic eating, and refusal to accept opened packaged food portions due to fear of tampering.

Enjoy the opportunity to form a long-standing relationship with the Survivor and his or her family. Follow up thoroughly on all food and food service issues. These are often critical to the long-term clinical nutrition outcome for the Survivor.

Tips for Servers and Other Staff Who Assist with Meals and Snacks in an Institutional Setting

Communicate on an ongoing basis. Offer as wide a variety of food choices as possible and provide enough assistance with eating to promote the client's autonomy. Avoid running out of a food item as this may trigger frightening memories of shortages and deprivation. You may wish to refer to individual menus and describe the next meal that will be served. This may reassure Survivors, who lived in an atmosphere of painful uncertainty for so long, that the next meal and the meal after that will be there "for sure." Always check that the Survivor is finished with the dish or the tray before removing it. If removal of food provokes anxiety, it may be necessary to leave an item such as juice or crackers so that the person is left with some food a form of comfort and reassurance.

Discreetly check rooms and drawers for hidden food. Offer "safer" foods - those that will not spoil so readily, such as packages of crackers - for hoarding activity as needed. Be tolerant and respectful of this practice. The Survivor's need to sleep with a piece of bread under the pillow is a deeply ingrained and poignant behaviour

Maintain a calm, gentle, reassuring and cheerful demeanor. Identify yourself and orient the individual to the meal. For example: "Hello Mrs. Cohen, I'm Donna, your server. I hope you enjoy your dinner today. We have __________ on the menu." Then show or describe the menu choices. You may have to observe and listen for cues about the preferred choice if the person's response is not easily determined). As much as possible, the same staff should serve food, providing continuity of service. This helps staff get to know each client, to remember their likes and dislikes. Orient residents to the food being served: "I hope you enjoy your chicken." A light touch on the forearm is helpful, visible and non-threatening, and can enhance food intake.

Add the elements of fun, joy, intimacy, respect and dignity. This can be possible every day, but is especially important during celebrations, holidays and other special occasions. The client should not have to miss out on daily activities and routines which are so important to quality of life.

Understand that food and mealtimes are a special focus for many Survivors. Show empathy and remember how important your role is in contributing to the daily life of the individual resident. Do not personalize any reactions that may be triggered by Holocaust associations or exacerbated by progressive illness and cognitive decline. Work to maintain a good and supportive rapport with Survivor families. Know about the resources available to you and how to access them when you need support in working with these clients.

The Speech Language Pathologist's Perspective

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The Speech Language Pathologist (SLP) might work with older Survivors in the community and/or the hospital or nursing home. SLPs have a dual care role. They provide assessment and treatment of communication (speech and language) disorders and also assess and manage swallowing. This work is critical to well-being since it focuses on aspects of both communication and nutrition.

SLPs should be aware of certain factors that have potential to affect communication by and with Holocaust Survivors. Frequent retelling of Holocaust experiences is not uncommon. Survivors who live with dementia may confuse recent memories with their recollections of past traumas. This process may be impacted by neurological conditions in which repetitious behaviours (perseverations) occur. These may include the involuntary repetition of words and actions.

Many Holocaust Survivors speak a number of languages. With dementia, language abilities are often affected, and it is common for multilingual clients with dementia to start confusing languages they have known and used all their lives. As long as potential underlying causes for the retelling are identified, a communication partner can support a client by listening and redirecting the telling in "safer" directions. SLPs are there to support family members and other caregivers in identifying causes, understanding communication behaviours, and using appropriate and helpful communication strategies.

SLPs and dieticians are often involved when clients have dysphagia (swallowing problems). They help staff and families deal with issues surrounding food and, in some cases, the decision about whether to insert a feeding tube. Change in diet can be an extremely emotional topic for Holocaust Survivors and their families. They may not be able to accept recommendations such as change of diet texture or changes in serving or feeding strategies (ie. the use of special utensils).

Limiting food choices, often recommended for patients with dysphagia, may be seen as removing the Survivor's freedom and independence. Wherever possible, the Survivor, supported by SLPs, dieticians and other caregivers, should be encouraged to make such decisions. Careful, detailed explanations outlining the rationale for diet changes or other interventions are important for both the Survivor and family members. It is helpful to limit such discussions to the client's present situation, emphasizing current concerns in order to lessen negative associations with past traumas and memories of deprivation.

SLPs who contribute their expertise to decisions about tube feeding often encounter two seemingly contradictory reactions among Survivor families. On the one hand, there may be a desire to "feed at all costs" because of privation experienced during the Holocaust: "My mother starved during the War ... how can I let her starve now?" On the other hand, family members may be concerned that their loved one will suffer as a result of the procedure: "My mother suffered so much during the War. I do not want to prolong her suffering. We do not want a feeding tube."

Concerns regarding food deprivation and physical pain are recurring themes for Holocaust

Survivors. The SLP needs to be aware of these themes and provide information that will support family members in making the best decision. An ethics committee serves an important function in some health care facilities, advising care teams on how to support families in these difficult circumstances. An SLP is an important contributor to the ethics committee in a long-term care institution.

We should be aware that many Holocaust Survivors are reluctant to report feeling unwell, which they perceive as an admission of weakness; in the concentration camps the weak and unwell were sent to the gas chambers. Clinicians working with Survivors must develop supportive yet probing and flexible interview techniques to gain the information necessary for the provision of appropriate, sensitive care.

Case study: Swallowing, Mr. Y

Mr. Y., an 80 year-old man who resides in a long-term care facility, was referred for a swallowing assessment due to coughing at mealtime. He had a history of stroke with relatively intact cognition and ability to communicate. Initially the SLP had difficulty obtaining a detailed history as Mr. Y. indicated he did not want to complain. He told her: "They are feeding me now. I didn't eat for weeks. You know that I was in the War." Mr.Y. was unable to tell the SLP what his specific eating problem was - that is, whether he coughed while eating solids or fluids or both. He was concerned that something would be taken away from him, possibly his food or his care, if his "weakness" became known. Mr. Y. asked the SLP many questions, seemingly to get to know her and to establish trust. In response, the SLP spent extra time with Mr. Y. answering his questions, listening to his War-time history, and observing him at meals to obtain information she could not get from the initial interview. With Mr Y.'s consent, the SLP met with family and staff members to get information that Mr. Y. could not provide.

After the assessment, the SLP recommended restricted food textures (minced food, no bread or hard-to-chew items) to ensure Mr. Y's safety while eating. He frequently requested food items that were unsafe for him. When he went to the communal dining room, he was in the habit of taking along a plastic container, which he filled with leftovers, including the unsafe food items. After programs, Mr. Y gathered plates of leftover cookies, fruit and other foods that he later stored in his refrigerator. Yet he rarely ate the food he collected. When asked about this, he said, "You never know when you will need food. During the War we often did not have food." He was not concerned about the stored food being unsafe to eat. In fact, he did not throw it out even after it spoiled.

Issues Raised in Swallowing Case Study

- physical change due to stroke
- emotional issues regarding trust
- history of personal hardship which may exacerbate fears ordinarily associated with initial institutionalization.

The specific issues raised in this case:

Memories of lack of food/starvation. Mr. Y. didn't eat for weeks during the War. During his swallowing assessment, he was reluctant to discuss his swallowing problems for fear that food might be taken away from him.

Hoarding of food Despite food texture restrictions recommended for his own safety, Mr. Y.

hoarded food, including items deemed by SLPs to be unsafe, in order to ensure that he wouldn't starve.

Mistrust of health care providers. Mr. Y. showed fear and distrust of people in uniforms and those in positions of control. It was necessary to spend additional time with him, building trust so he would feel more comfortable describing his swallowing difficulties.

Fear of change in diet or food texture. Mr. Y was placed on restricted food textures to ensure safety when eating. When familiar food was taken away from him, this triggered fears of loss, deprivation, hunger and starvation.

Case study: Cognition/Communication, Mrs. K.

Mrs. K., an 82 year-old woman, was referred for out-patient treatment of speech problems (dysarthria) related to her Parkinson's disease. She was also showing signs of cognitive changes, including confusion of English with her native Hungarian and Yiddish. She displayed impairment of recent memory and frequently told and re-told personal accounts of her Holocaust experiences.

When questioned, Mrs. K. did not report having any difficulty with her speech. During interviews, she seemed to have trouble focusing on topics of conversation and activities set in the present. She was unable to accept her Parkinson's disease, fearing that an appearance of weakness (having a disease) might make her vulnerable. She expressed that she "did not need help."

In therapy, the SLP supported Mrs. K. by focusing on present treatment tasks which included helping her talk more loudly and audibly to others. During each session the SLP allowed time for Mrs. K. to talk about her past, then dedicated most of the session time to speech therapy so she could achieve her voice and speech goals. Mrs. K. met with a Social Worker regularly. In these meetings she had the opportunity to speak of her past and her Holocaust experience. In this way, the appropriate professionals addressed both her emotional and speech needs.

Issues Raised in Cognition/Communication Case Study

- dysarthria
- reluctance to accept her diagnosis and to receive help
- language confusion due to cognitive impairment
- history of personal hardship
- The specific issues raised in this case:

Difficulty accepting a diagnosis. It was especially hard for Mrs. K. to accept the fact that her memory was impaired. Because of her Holocaust history, she likely perceived that being unable to remember would almost certainly make her appear vulnerable and putt her life at risk.

Confusion of languages. For Mrs. K., this loss may limit her ability to socialize, to feel part of her current culture and to interact with her grandchildren and others.

Expression of independence and "no need" for get help. Mrs. K. survived the War by being independent and always understood that dependence would be dangerous and out of character. Even in her 80s, she prefers to conceal her difficulties rather than admit weakness.

Speaking in a louder voice. Mrs. K. did not take part in treatment for purpose until a multidisciplinary approach was employed. The SLP could only start working to normalize her speech once Mrs. K. began meeting regularly with a Social Worker to talk about her past experiences and her present fears.

Tips for Speech Language Pathologists

Always introduce yourself and explain clearly why you are there. If you are doing a procedure, explain it, show the items you will be using and describe your actions as they occur.

Become familiar with the client's background and possible exposure to trauma - for example, is he or she a Holocaust Survivor from a concentration camp, a survivor of torture or some other conflict?) This will allow you to respond appropriately if the topic comes up in conversation with the client or family.

Recognize that it may take time for the person get to know and trust you. Those with cognitive impairment may require more time.

If appropriate and with the client's permission, speak to family/friends to gain more information about his or her life. Knowledge of the person's history will assist you in adjusting your communication style and strategies for effective interaction supporting the treatment activities.

Focus on and reinforce client strengths to overcome reluctance to accept help.

Be aware that complex reasons may exist when a client refuses a particular treatment recommendation. In the case of Mrs. K., she did not wish to make use of speech therapy initially. Sometimes, family members who want to allay an elderly parent's starvation may decide to asking for feeding tube insertion against the advice of health professionals. Make an effort to validate client and family reasons for declining treatment recommendations and suggestions.

Support client and family learning and decision-making by providing written information on recommendations and reasons for suggested changes in diet or activities.

Offer alternatives and allow time for decision-making. SLPs should involve family and friends where appropriate. It may take several sessions to present and reinforce the information and to implement the recommendations. Patience is very important.

Be an active listener. If a client needs to talk about his or her past, accommodate this desire. But if they do not wish to talk, respect that choice, too.

When appropriate, rely on the expertise of other members of the team to assist with clients who are resistant to treatment.

Tips to Assist with the Acceptance of Swallowing/Safety Recommendations

Don't fight food hoarding. Arrange to maintain fresh and suitable food in the client's room. In most situations, a symbolic portion will reassure anxious Survivors that that food will continue to be available.

Provide alternatives for diet change and be aware that diet changes are lifestyle changes which may have a particularly strong impact on Survivors.

Remember that limiting food choices may be interpreted as taking away freedom and independence. Some Survivors may interpret such actions as an attempt to starve them once again.

Tips for Communication/Cognition

Use gestures, pictures, written keywords and objects to assist with understanding.

Use a comforting voice and describe what is happening.

It is helpful in treating Survivors to identify their best language and remind them to use that language for communicating with staff. If necessary, it may be helpful to use an interpreter for assessment and treatment as even individuals who were fluent in English can lose some of their fluency if they have dementia.

The Occupational Therapists Perspective

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As occupational therapists we recognize the value and complexity of occupation in peoples lives. Engaging in meaningful occupations is essential to our health and well-being. We understand that people need to do something. What they do gives meaning to life and speaks to the core of what everyday living is all about. Our occupations change over time and are shaped by both internal and external factors such as circumstances, environments and experiences.

The Occupational Therapist (OT) who works with a Holocaust Survivor needs to gain a good understanding of how the individual's personal experience has affected his or her life perspective and their ability to engage in meaningful occupation. A powerful link between each human being's need for occupation and survival through the Holocaust is illustrated by Victor Frankl's desire to complete his written work and the re-creation of his manuscript. This kept him from losing hope in what seemed an otherwise hopeless situation.

As Survivors who lost loved ones in the War age, past feelings of loss and grief may surface and affect how they cope with current day-to-day living. They may feel the effects of loss when they confront changes in physical and mental health. This may impact on their recovery from illness or how they adjust to disability in ways that are unique to Survivors as a group. The Holocaust Survivor may experience memories triggered by objects, events or occurrences which are harmless or meaningless to everyone else. Occupational therapists can facilitate an understanding of this through our interviews and by observing clients engaging in their everyday occupations.

Occupational therapy services focus on enabling occupation. Occupational therapists work with the aging population to provide opportunities for them to engage in meaningful occupation, even though their abilities may be changing. OTs understand the need to be aware of the unique culture and community of each client. The meanings that people give to occupation are shaped in part by their socio-cultural world views and their experiences.

The client-centered practice used by occupational therapists is based on the concept of active client participation and power which is shared between therapist and client. We work with clients to find out what is important to them, to identify factors that have helped shape who they are, and to determine what supports might enable their important occupations. OTs work with our clients to create possibilities and opportunities that in turn help them develop capabilities. These capabilities allow them to do what they need, want and are expected to do in their daily lives.

Certain processes can help us in our work with older clients, including those who have lived through the Holocaust. As part of the assessment process, the OT may use a narrative, semi-structured inquiry to gather information about who the client is, what he or she has done, and their "experience of doing." This process can help illustrate factors that have shaped the persons life and uncover strategies they have used to cope in times of stress.

The OT may provide opportunities for the client to share stories as a way of learning more about their occupations. This process may also assist with occupational performance issue identification, which can set a context for the client's goals and help clarify how an occupational therapist can help. A practice model that can guide the occupational therapy process is the occupational performance process model developed by Fearing, Law & Clark (1997). Using measures of occupational performance based on a client-centered approach to practice (such as the Canadian Occupational Performance Measure) supports and facilitates the identification and measurement of change in clients' performance of their occupational goals.

OTs work with clients to identify meaningful occupational goals and explore barriers to achieving meaningful occupations. An understanding of the impact of the Holocaust experience and the triggers that are significant for them are important in the therapy process. Knowing how the Holocaust has shaped and impacted a person's occupations can provide important evidence to OTs as they work with clients who are Survivors. Understanding the meaning that the client attributes to his or her War-time experiences provides the therapist with invaluable information to guide the therapy process and ultimately help meet the clients needs.

A Personal Perspective

As an occupational therapist and as a child of a Holocaust Survivor, I am in contact with Survivors, both professionally and intimately, every day of my life. I believe that it is imperative that the OT has an understanding of the Holocaust and the wide variety of personal experiences that a Survivor may have lived through, both during and after the War. Survivors of the Holocaust belong to an aging population that faces age-relate physical decline. This decline may bring new challenges, which are often compounded by ongoing feelings of helplessness or loss. Many Survivors managed to put their lives back together after the War, but find themselves unable to muster enough strength to do it yet again, when they lose a loved one, or suffer a new physical challenge due to illness. In fact, these new losses may be compounded and magnified by old losses, and this can make recovery or adjustment even more difficult than it would be for someone without this history of traumatic, overwhelming loss.

The atrocities of the War meant Survivors lived through a multitude of unspeakable experiences. Even though they survived and moved on, they may carry these thoughts, images and feelings with them through each day and every night of the rest of their lives. As was mentioned in the previous section, objects, events or occurrences that many of us take for granted have the power to trigger vivid memories and nightmares of the Holocaust. For example, medical staff and health care facilities, may conjure up unmentionable recollections, such as medical experimentation. Aging, illness and subsequent losses, as well as the fact of one's mortality, can make life seem more difficult than ever before.

As a person ages, there may be an imminent "fear of the institution," which is seen as a place in which they will be put away, to be forgotten and die. Many children of Survivors know the intimate details of their parents' past nightmares and their continuing struggle to deal with their suffering. For this reason, their instincts often include a desire to protect their parents from any further pain. As their parents age, the challenges become even more demanding, and children may not have the resources and skills to fully care for their aging parents. They often deal with conflicting feelings: they want to provide care for their parents, but don't wanting to "put them away" for fear of re-creating trauma.

Occupational therapists should recognize and respect these feelings. If a choice is finally made to institutionalize an elderly Survivor, the children should be encouraged to become involved in the care planning process. This will help decrease anxiety about entering a new environment and minimize feelings of isolation by maintaining the close bond between the Survivor and their children. The Survivor and his/her family should be partners in decision-making. Such a client-centred approach to treatment is paramount to Survivors because it promotes a feeling of control over the environment.

Often Survivors will recount that they found the strength to live so that one day they could tell their stories. Unfortunately, once the War was over, many Survivors confronted a troubling phenomenon: they were not accepted, not allowed to talk about their experiences, made to feel guilty about not fighting back during the War, or made to feel uncomfortable about being a foreigner in a new society.

In Israel, Survivors were nicknamed the "Vusnikes," a term derived from the Yiddish expression, "Vus sukste." This phrase was used when an immigrant did not understand some new custom in the new country. They were discouraged from telling their stories, because many people did not want to hear yet another recounting of horrors experienced by their own relatives and fellow Jews.

When the Survivors started new families of their own, many could not bring themselves to discuss these atrocities to their own children. As an occupational therapist, I have found that many of my clients have prefaced sharing their stories with me by saying they have been unable - or found it too difficult - to speak about such things to their own children. I feel that we should provide a milieu which allows for open recounting of stories. As professionals and, in some cases, fellow travelers, we can offer a compassionate ear to clients who not only suffer their current challenges, but also face every day of their lives with memories which resemble nightmares.

If the motivation is there, Survivors can be encouraged to write or record their experiences that can then be shared with their family members or used to educate others. Conversely, if the Survivor does not wish to share these experiences, that desire should be respected as well. In the extreme cases, if the stories prevent normal functioning, then the therapist may want to refer the Survivor to an appropriate support group or specialized therapist for in-depth counseling.

As a therapist, one should acquire a keen understanding of the historical events surrounding the Holocaust and become acquainted with personal accounts of Survivors. Only then can we begin to understand the varied reactions that Survivors may have, so that we in turn can become the supportive listeners they need.

It is important to note that the Survivor is just that - a Survivor. The word means "one who outlives." This implies inner strength and resourcefulness. Thus it is paramount for the therapist to help direct Survivors' ability to reach within themselves, to tap deep, inner strengths, and to focus on the positive aspects of life - personal accomplishments, family - so they can also feel enjoyment, fulfillment and quality in their lives.

Case study: Mrs. C.

Mrs. C. is 79 year-old married Holocaust Survivor. She was diagnosed with dementia two years ago. She has two adult children who live in the same city as she does. She lives in a condominium with her husband, and has a paid caregiver who is with her daily for six hours. She sees her children weekly for the Sabbath meal at one of their homes, and her daughter drops in regularly with the grandchildren. She has some heart problems, and the doctor has arranged for home care help with bathing, and also to obtain regular blood samples. Mrs. C. usually becomes upset, crying and moaning when the lab technician and home care worker appear weekly.

Recently, she has become much more memory-impaired, and her husband has had to help her with many activities. Her sleep is not as good as it was, and she awakens very early in the morning. Her husband is now more tired in caring for her. She talks often about her family of origin and her experiences during the War. She fondly talks about certain family members whom she liked. She also talks about how much she enjoyed caring for her family and mourns the loss of her role as a cook and baker. She would previously make large Sabbath meals for all.

Her husband has arthritis and is feeling the stress of care giving. He too is a Survivor and is contending with painful memories. At the War's end, Mr. and Mrs. C. each promised to always remain at the other's side. This promise now weighs heavily on Mr. C.as he struggles to plan the future. Mrs. C. can become physically agitated, and more recently has developed some repetitive hand movements. She seems unable to sit still for long periods of time.

The occupational therapist is asked to assess Mrs. C.'s needs and to make recommendations which will help the couple cope with their present situation.

Issues Raised in Case Study

- the need to look at the person from the holistic perspective, and understand the individual's past
- the possible presence of environmental triggers and the role an OT might play in utilizing the client's environment in a positive manner
- the importance of ensuring the client has a sense of control over her activities and environment
- the importance of utilizing appropriate communication techniques
- the role of meaningful occupation and choosing activities that promote a sense of accomplishment, that enhance self-esteem, and that nurture a sense of self
- the role of OT as an educator to others including other professionals as well as client and family
- the need to capitalize on strengths as well as adapt to weakness
- the constant need to respond to changes in the client and her current environment

Addressing the Issues Raised in the Case Study

The case demonstrates several issues that can arise when caring for elderly Holocaust Survivors. Mrs. C. has lost her ability to retain new information, and her memory is focused more on the past than the present. She is obviously revisiting her past experiences, both prior to and after the War. The goal of therapy is to help her balance the innate need to live in the past with her life at present. The occupational therapist suggests that Mrs. C.'s family engages their mother in reminiscing techniques, as well as activities that will help her feel more involved in the present. For example, under the supervision of her daughter, Mrs. C. is encouraged to bake with her grandchildren. This is something that she always loved to do and it allows her to participate in the Sabbath meal.

The grandchildren are also encouraged to show Mrs. C. old photos of herself and her family and to ask her to talk about the pictures, an activity which she also enjoyed in the past.

The community therapist instructs home care staff who work with Mrs. C. in how to introduce themselves and reorient her to the nature of their visit each they come. This is necessary because she usually forgets who they are once they leave. A relaxed approach, letting her take control of simple activities - folding towels, using soaps and lotions - is calming to her. The lab technician is asked not to wear her lab coat when she visits Mrs. C. at home, as it elicits memories of medical experimentation which she experienced in the concentration camps.

Mrs. C.'s husband, who also survived the War, is torn and stressed by the physical and emotional burden of caring for his wife. They have promised never to leave each other, but he realizes that his children are right, that institutionalization is imminent and necessary. He requires a lot of education and support to help him with the impending separation. He also needs help dealing with the loss of his wife as he once knew her. Old feelings of abandonment and separation often come to the surface because of this couple's Holocaust experiences.

Mrs. C. often talks about her family of origin, including her mother and father who perished in the camps. She has also started to have some repetitive hand movements and these are best redirected into a meaningful occupation. It was noted in an interview that Mrs. C.'s past vocation was as a seamstress. She had helped her mother sew in their family's tailor shop before the War. She is given small challah (bread) covers to embroider, which she can do this for brief periods, stopping when she becomes tired. This activity is a helpful, productive and relevant way to allow Mrs. C. to enjoy good feelings from her past, yet focusing her on a current activity.

Mrs. C. is also encouraged to take advantage of her good physical health, to move out into the community and the world in which she is living for now. The local community centre and synagogue are appropriate destinations, so long as she is in the company of the caregiver or a family member. These outings give her a sense of purpose and decrease her agitation. She is also sleeping better due to the walks.

This family will require ongoing support. Plans should be made to re-evaluate Mrs. C.'s activities and the appropriateness of her current surroundings, especially if her cognitive and /or physical health decline.

Tips for Occupational Therapists

Occupation gives meaning to life. As such, it is an important determinant of health and well-being. Together with our clients we address the impact of illness, injury, and other adversities on the person's ability to carry out old and new occupations.

We all have an inherent need to do things in our daily life. This is part of who we are as individuals, and also who we are within our families and communities. These activities define our uniqueness, and form basis of our relationships, both with ourselves with one another. The Holocaust Survivor is no exception. However, OTs must be aware how the past might impact this person's daily living. Below are some useful tips to remember when working with the aging Holocaust Survivor.

Initiating the Client-Centered Relationship

Be aware of how you present to clients and families. Always explain your role as an occupational therapist to the Survivor. Remember, the Survivor may not be used to accepting help. Help can be construed as a sign of weakness; the person may feel the idea of accepting help is a sign of their inability to manage.

Do not be surprised if clients don't see "the point". The Survivor may feel: "This problem of mine is nothing compared to what I have lived through." Be patient, and frame the situation for them. Help them see how accepting your involvement will encourage their ongoing strength, and not contribute to an appearance of weakness.

Illness may be equated with death, and this concept is often especially difficult for Holocaust

Survivors. Be sensitive to the role you play in the person's definition of himself or herself as ill or elderly. Understand that these two groups were not allowed (nor could they) live through the atrocities of the Holocaust.

You may elicit a response from clients just by who you are. The Survivor may bestow upon you qualities that may or may not be accurate based on your looks or cultural background. Meeting a therapist who is blonde and blue-eyed can revive old memories of how being Aryan was valued. It may also bring out fears about how you as a therapist may behave towards them.

Provide good listening and empathetic support. Yes, this applies to all therapeutic relationships, but Survivors have usually lost so much already that their tolerance and pain threshold may be unusually low. Encourage them feel that it is safe to share information and feelings which might be necessary and helpful.

Awareness of Environmental Triggers

Understanding the concept of environmental triggers is very important if you are working with elderly Survivors. The importance of freedom is often different for a Survivor. A simple occupational therapy safety technique - placing a lock on the door of a wanderer - may elicit a strong negative reaction from a Holocaust Survivor but not from someone who did not experience the War.

Look for triggers in the routine. As a therapist, review the person's daily schedule and activities. Strict schedules may conjure up memories from labor or concentration camps. So may staff uniforms.

Remember that even simple activities of daily living can trigger positive and negative feelings. Dressing and undressing in front of someone may be laden with painful memories for a Survivor whose body was not respected, and possibly even used for medical experimentation.

Key Approach Strategies

Use the environment to elicit positive memories. Although the environment can trigger negative behavior, it can also remind the Survivor of successes, meaningful relationships and positive events. Be aware of this tenuous balance between good and bad memories. Choose and analyze activities accordingly.

Provide activities that build on successes and accomplishments. The Survivor may need extra help in this area, especially if memories pull them back to a painful past. Ensure that the chosen activities are valuable and reinforce the many abilities that remain.

Promote choices and feeling of control. This, too, is not a unique therapy principle, but may be especially important for Survivors who felt out of control during the Holocaust. More than others, they may place great value on having choices over small things.

Ensure the Survivor has opportunity to meet and spend time with others to whom they best relate. This might be a certain family member, a friend, a volunteer or a fellow client. Many Survivors feel a sense of connection with others who have some special understanding of what they have been through.

Seek good support for yourself as a professional. Working with the Holocaust Survivor can be draining and emotionally taxing. Do not neglect your own need to talk about this with your colleagues and with others who have had this experience.

The Physiotherapist's Perspective

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Physiotherapists are movement specialists. Passive and active movement is essential for the maintenance of physical health and emotional well-being. Aside from the obvious benefits of maintaining or improving strength, flexibility, and endurance, exercise can also improve circulation, metabolism and digestion. It can help ease muscle spasm and improve tone. It can help prevent joint and soft tissue contractures, blood clots and other circulatory problems. Movement is both enjoyable and rewarding, and is a major factor in quality of life.

Physiotherapists may work with clients following an illness or accident in order to help achieve an optimum recovery, or with clients with chronic illness to help maintain function and prevent deterioration. Physiotherapists work closely with the client and client's family in the assessment and planning of an individualized program. Goals are set collaboratively, and must be realistic, measurable, and in most cases, time-limited.

Many Holocaust Survivors work willingly with the physiotherapist, as the concept of goal oriented 'work' is a familiar one. At the same time, the physiotherapist first interaction with the Survivor may be at a very vulnerable and frightening time, such as post illness or post trauma. As part of her/his overall assessment, the therapist must be sensitive to the client's Wartime physical challenges and the post War recovery process. All treatment plans and options must be carefully explained and clarified so that the client understands all aspects of the treatment and how they all relate to the end goal. Goal setting should be done in collaboration with the client where possible, always involving the family when not possible. The importance of emphasizing realistic goals cannot be underestimated.

The families of Survivors are often very involved in their parents' treatment and recovery programs. The issues and some of the reasons for this involvement have been described in previous chapters. The physiotherapist should be cognizant of this and wherever possible, involve the relevant family members in the treatment and care plan. It is important that the family also understand the rationale behind various treatment approaches.

A key component to all physiotherapy intervention is comprehensive physical assessment of the client. This is essential in determining baseline status, in helping to set treatment goals and the treatment plan. Typically, the therapist will perform this assessment either in a small examination room or by drawing curtains around the client for privacy. For some Holocaust Survivors, this may induce memories of horrific medical experimentation. Avoiding medical language such "test," "measures," or "assess," may help prevent such connections. Alternately, evaluating specific functions in a more natural setting may be the best approach with some clients. For example, rather than performing a Berg Balance Test or a 2-minute walk test, spend a little time getting to know the client first, then take him/her out for a walk on the street to assess balance and gait.

Gait training is another very common activity for physiotherapists. A training technique that is often used is to stand behind the client giving verbal cues to remind him to set a pace and to take the next step. Walking behind the client saying " left - right - left - right" may invoke memories such as a death march. Wherever possible, be conscious of your terminology and make a point of being aware of reactive cues from your client.

Case Study: Mrs. C.

Mrs. C. is an 87-year-old woman who survived the Holocaust by hiding in the woods. She had jumped off a train enroute to Auschwitz, been shot by the Nazi guards and left for dead. The train moved on. A small group of partisan fighter hiding in the woods saw this, dragged her to safety and nursed her for the duration of the War. She survived but with a badly atrophied and damaged leg that inhibited her movement ever since. She walked with a severe limp, dragging her leg, putting her body off balance. Accommodating this left her with life long chronic pain and left sided weakness.

She had a remarkable outlook on life, and was determined that her disability never be a handicap. She later married, raised three children and after her husband died, maintained the family home with fierce independence. Once in her eighties she began falling more often. She curtailed her outings, moved around less and also became weaker. Reluctantly, she agreed to use a walker, but did so inconsistently. Most recently she fell and broke her hip, was hospitalized and now post surgery was in a rehabilitation unit working with a physiotherapist and related team members, with her stated goal of returning home. Due to her advanced age, increased frailty and pre-existing injuries, the prognosis for Mrs. C. was guarded. The care team felt Mrs. C. may have to move to supportive housing. However, Mrs. C. was determined to get back on her feet, go home and maintain her independence. The physiotherapist was working on ambulation with Mrs. C. with discussion of a need for an electric wheelchair. Mrs. C. waited impatiently each day for the physiotherapist's visit so that she could increase her strength and facilitate her recovery.

Issues Raised in Case Study:

- The War had left indelible scars on Mrs. C., yet she had overcome many of the obstacles by sheer perseverance and commitment
- Mrs. C. had a pre-existing vulnerability (her damaged leg) that would impact on recovery
- Mrs. C. had created a lifestyle for herself that ignored chronic pain and overcame her physical disabilities.
- Mrs. C. believed that determination and perseverance could overcome all obstacles
- Mrs. C. lives alone and would be at risk for further falls.
- Mrs. C. was not recognizing her increased frailty

Tips for the Physiotherapist:

Client education is essential. Diagrams, verbal explanations, photos etc. would all contribute to a client's ability to hear and understand unwelcome news.

Everyone has trouble accepting diminished physical mobility and changes to their health status. There may be larger implications for the Survivor, as during the War the physically vulnerable were either put to death immediately or could not survive the subsequent hardships.

In the case of Mrs. C., her experience had shown her that if you persevere enough, you could manage. The physiotherapist may have to dedicate extra time to support her understanding that this time, excessive exercise without the appropriate aids could injure her further.

Whenever possible, offer the client choices on what they will work on in any given day; ask ... "Would you like to practice walking today, or would you like to work on your balance? The client will appreciate this sense of control. Avoid using encouraging phrases such as "work hard" or "I know this is hard work" ... this may invoke a strong and resentful negative reaction such as "you don't know what hard work really is!" Instead use phrases such as "you are doing well" or "I know you are trying."

In general, avoid rushing your clients; they will often need more time to process information before they can respond with a movement or with a verbal response.

The Therapeutic Recreationist's Perspective

Arlene Sanders, Bobbi Cohen, Michelle Eisner, B.A., Dip. TR, Baycrest Centre

Therapeutic Recreation is a process that utilizes treatment, education and recreation participation to enable people with physical, cognitive, emotional and /or social limitations to acquire and/or maintain the skills knowledge and behaviours that will allow them to enjoy their leisure optimally, function independently with the least amount of assistance and participate as fully as possible in society. (Therapeutic Recreation Ontario).

The Therapeutic Recreationist (TR) might work with older Survivors in the Community, a hospital, retirement home or other long-term care facility. The primary role of the TR is to provide recreational programming that addresses a person from a holistic perspective. This includes their physical, social, emotional, intellectual, cognitive and spiritual needs.

Within the framework of recreational programs, the Survivor may react to words, phrases, music, physical touch, and/or news (for example, the events of September 11, 2001). Reactions range from pleasure to distress, depending on the individual and the circumstances. Certain holidays or specific programs could trigger memories that are upsetting or distressing for a Survivor. The role of the TR is to create a leisure activity environment that avoids potential triggers. He or she should also be aware of adverse reactions, and if they occur, respond appropriately and sensitively.

Institutional Case Study; Mrs. H.

Mrs. H. is an 83-year-old Holocaust Survivor who was born in Romania. Mrs. H. has lived in Canada for over 20 years with her husband and daughter. She lived independently and loved to cook and bake. Mrs. H. suffered a stroke in 1998 and as a result became aphasic. She is no longer able to speak. This necessitated placement in a Jewish Nursing Home.

Mrs. H. communicates via gestures and eye movement. She is a positive, friendly and upbeat woman who enjoys attending a variety of programs. Her daughter is very involved and visits Mrs. H. every day. She encourages her mother to attend programs and events.

Mrs. H. really likes the music programs which take place on her floor. However, at times songs are sung which remind her of her lost family and of better times and which bring back painful memories. When this occurs, Mrs. H. cries and becomes visibly upset. When asked if she is all right, Mrs. H. usually says "Yes," but will continue to cry. The challenge facing the TR is to determine whether her response is a positive one (she is moved and cries to achieve emotional release) or a negative one (she is possessed by her grief.)

Her husband is a regular visitor to the floor and accompanies his wife to recreation programs. He is a very angry, overbearing individual who often displays behaviour that has a negative impact on other program participants. He can be extremely critical of other residents, and often minimizes their abilities: "They don't know what their doing." Mr. H. is a deeply religious man who accompanies his wife to the Friday afternoon Sabbath program. He insists his wife be first to light the candles, criticizes other residents' abilities and becomes very upset if he witnesses a few pieces of lef over bread being thrown away.

His feelings of entitlement set a negative tone during the program and upset the families and personal care workers in attendance. They can be heard muttering to each other about "Who does he think he is?" Most are not aware of his background. Others resent that he "uses" his past as a tool to get what he wants.

Mr. H. can usually be calmed if taken aside and spoken to gently but firmly about his behaviour. This situation usually is resolved for a few weeks and then the cycle resumes again.

Issues Raised in the Case Study

- acknowledgement of the client's feelings
- acknowledgement of the other participants' feelings
- how one responds to someone who cannot respond back
- quality of life of the individual
- respect, empowerment and dignity
- acknowledging and validating the feelings of the husband
- acknowledging and validating the feelings of the family members/companions
- inappropriate, disruptive behaviour of the husband
- client's entitlement to have her husband attend programs with her
- refocus husband's issues into a positive role

The Role of the Therapeutic Recreationist

Know Your Client Understanding the Survivor's medical history and background can help the TR see this person in a holistic way. This helps us understand each client's needs and provide the best possible care. Also, a positive rapport with the individual client should be developed to ensure trust, and to lay the foundation for a positive and beneficial working relationship. Developing a trust with the TR may help the client form trusting relationships with other the members of the care team. It is important to help the client to feel comfortable and secure. From a TR perspective, we want the client to feel that we are approachable, ready to assist and to care. Knowing and understanding the background and personality of family members is also vital, especially if they actively participate during programs.

Validate Client's Feelings A "client" might be a patient, resident, member, family member, volunteer or private personal care worker. Whoever they are, clients need to know that their thoughts and feelings are "okay." They need to know that someone is listening to them and trying to help them.

In the case of Mrs. H., this is difficult because she is unable to communicate verbally. Therefore, the TR's role is to assess body language including facial expressions, gestures and eye movement. When a client is able to articulate feelings, communication is much easier and the TR can respond more readily to client need. In the case of Mrs. H. and other non-verbal clients, some creative guesswork may be necessary, and the TR will always work in consultation with the entire Care Team. Being familiar with the client's likes, dislikes and daily routines will make all forms of effective communication easier. Validation lets the client know that their feelings are important, accepted and real.

Using Physical Touch. Always know your client before using any form of physical contact, since each person will respond differently touch. Culturally, physical touch is important to many Holocaust Survivors. Many Survivors feel especially isolated in unfamiliar surroundings and will respond by withdrawing further. When appropriate, physical touch can be rewarding, caring and supportive. However, physical touch may be inappropriate when interacting with someone who has an Orthodox Jewish background. Be aware of how your client responds to touch - it can be a powerful communication tool when it is used appropriately and respectfully. Touch can acknowledge and validate feelings. This can be as simple as a light touch or a hug.

Remember that family members are also part of your client system. Following one of his outbursts, Mr. H. was taken aside and the situation discussed calmly and with sensitivity. His past and current losses and his ears were acknowledged, along with his need to control situations. He was unaware that his behaviour was having such an impact on program and was upsetting others in the room. Once he realized the problems he was creating, he was willing to discuss making changes, including assisting the TR during programs. Clear and concise guidelines and limits were set. His role now is to say the blessing over the wine weekly and to assist by bringing patients to the table for the ritual candle-lighting service.

Include the entire team in decisions. An informal meeting with family members, private care workers and volunteers was held after one program to explain Mr. H.'s outburst and staff's responses to these events. Most were not aware of his history, his many losses, his need to be in control of the situation at all times and his inability to tolerate food waste, after having been starved for many years. Although they found it difficult to condone his behaviour and found it upsetting, they were willing to be more understanding, now that they had a fuller explanation. They were also willing to give him the opportunity to change. While this discussion was crucial to their ability to include Mr. H., his right to confidentiality must also be respected.

Reinforce the positive It is important to continually reinforce the positive role Mr. H. has adopted, and if the troublesome behaviour re-occurs, to reinforce the guidelines.

Community Case Study: Mrs. W.

Mrs. W. was originally from France, and when the War broke out, she spent several months in hiding. She was eventually discovered and deported to Auschwitz concentration camp. After liberation she found only a few cousins had survived and decided to emigrate to the U.S. She met her husband, who was also French, in the DP camp while were waiting their travel papers. They were married there, and she arrived in her adopted country, the U.S., expecting her first child.

Mr. and Mrs. W. worked long hours in their variety store in Brooklyn, N.Y. and provided well for their two children. Between work and caring for her family, Mrs. W. never had time for herself. She found that keeping busy kept her mind from wandering back to those times when she had a large and loving family and felt safe in her home town. While she maintained contact with a few Survivors from the DP Camp, both Mr. and Mrs. W. did not really have a social life. The business and the children were their focus and the source of their concern and their pride.

At the age of 72, Mr. W. suffered a fatal heart attack, and on the advice of her children, Mrs. W. subsequently sold the business. She then became depressed, and on the advice of her physician, joined a Fun and Fitness Program at the local community centre. She was a very reluctant attendee, explaining to the recreationist there that she "just didn't fit in," and that "she had nothing in common with these ladies." She felt different, isolated and heartbroken. She showed up every Tuesday and Thursday, with red eyes and a dejected look, explaining that she was there only because her doctor told her to attend.

Issues Raised in the Case Study

- Mrs. W. is still mourning the recent loss of her husband which is likely exacerbating her early life losses.
- Mrs. W. has no idea or experience with enjoying herself in a recreational setting.
- Mrs. W. feels no connection with the "American' participants" in the group.
- Mrs. W. isn't committed to attending.
- Mrs. W. needed support to discover a therapeutic recreational pastime that will be meaningful for her.

The Role of the Therapeutic Recreationist

Spend some time with the client on a 1:1 basis in order to understand her story and also her current challenges. Mrs. W. has never had the opportunity to mourn her family, her lost youth and her home, and now she is coping with the loss of her replacement lifestyle and everything she accomplished post-War. Recommend/create therapeutic recreational opportunities that might make sense to the client - for example, attending a Survivors Group (Cafe Europa), a French club, a spousal bereavement group.

Discover in conversations with the client what strengths she has now and which activities she takes pride in. Since Mrs. W. worked so successfully in the family variety store for so many years, she might enjoy volunteering in the community centre's coffee shop. Conversely, this may seem too much like work that no longer gives her pleasure. Instead, she might welcome the opportunity to discover new talents or hobbies.

If possible, include Mrs. W.'s children in a planning meeting how important it is for their mother to form new relationships and develop new interests. Such successes may help her children provide her with more positive reinforcement and facilitate the development of new connections.

Introduce the client to one or two other women who are also Survivors, so she will not feel so out of place. In partnership with Survivor participants, generate new programs of specific interest to Survivors, such as city-specific Koffee Klatches, or reminiscence groups that focus on positive memories.

Maintain regular individualized contact with the client as she becomes more comfortable in social group settings.

Tips for the Recreationist:

- Seek out positive attributes.
- Focus on abilities.
- Watch for adverse behaviour that impact negatively on others.
- Reinforce positive responses.
- Provide support to everyone involved.
- Know your client.
- Deal with the issues openly and honestly.
- Understand that people are entitled to their feelings and opinions.
- When appropriate, use physical touch.
- Share the information with the team.
- Feel positive about the process.
- Contribute to the creation of a safe and caring community.

The ultimate goal of the TR is to improve the Survivor's current quality of life by making a variety of programs available for the person's enjoyment. The TR provides opportunities to allow clients to preserve some of their autonomy. The principles that guide the TR's work include treating individuals with respect, enabling them to make their own decisions, maximizing their abilities, and treating them with dignity.

Activities to Maintain Well-being of Survivors

Paula David, MSW, Coordinator, Holocaust Resource Project, Baycrest Centre

Activity and Program Suggestions

Health promotion is a new concept for most seniors, but particularly so for Holocaust Survivors. The idea of "owning" our health by actively maintaining it and preventing disease may have great untapped potential.

Alternative therapies may help keep Survivors out of medical offices that are likely to trigger negative memories. Alternatives to conventional medicine can make Survivors feel good by facilitating the body's innate healing response. The concept of taking control of one's health and lifestyle (where possible) is an empowering direction for older adults. Older Survivors may thrive on a "wellness" model, since they were robbed of self-determination during the War.

Programs and activities that address the needs of mind, body and spirit will go a long way towards helping an older person maintain optimum health.

Arranging programs and activities for Survivor-specific groups may not always be possible or desirable. Individuals should be consulted about their feelings around participating in programs devised solely for Survivors and programs which welcome people from diverse backgrounds. A combination would be ideal, and where that is impractical, some attempt should be made to address the unique commonalities of Survivors.

Some examples of wellness-based activities are:

- social groups giving opportunity for reminiscence and connecting
- traveling groups offering day trips and organized vacations
- theatre groups
- choirs and music appreciation groups
- lunch Programs that involve planning, nutrition, socializing and sharing recipes
- adapted yoga
- dance therapy
- muscular relaxation exercises
- massage therapy
- breathing exercises
- calming recorded music
- affirmations - positive statements
- nutrition classes
- humour programs
- spiritual activities

The Survivors, by their very lives, have demonstrated the importance of discovering and maximizing our inner strength and resilience. It makes sense that a range of wellness opportunities would appeal to this those who spent their post-War lives maximizing their opportunities and investigating the range of their potential. Now that they are older and may be facing various physical or cognitive constraints, Survivors may need external supports and structures to maintain their resilience. Community centres, recreation staff and family members should look to creative ways to support aging Survivors. As long as there is flexibility and the ability to respond to a wide range of individual needs, then new and innovative programming and alternative treatments should be considered.

Survivors Groups

Whether formal or informal, groups can provide an empowering and healing environment for older adults. Survivors, as part of their coping mechanisms, formed natural support groups. In many instances, this served to replace lost family members.

Reconstructing an original family group was, in itself, a survival mechanism that served well for the post- War years. As Survivors of the Holocaust settled in new countries, new jobs and new homes, they formed new groups and new communities. The societies ("landsmenschaft") and the "clubs" provided social opportunities, substitute family members and circles of support where they could openly share their common nightmares. Now, more than 50 years later, these circles are growing smaller, and Survivors may need to find comfort in external supported group settings.

Organizing and running mutual aid and support groups with elderly members can prove challenging, regardless of the identified commonalties. When making a commitment to participate in a group, older adults must consider physical and cognitive abilities, as well as the realities of a labile health status. The group leader must recognize the vulnerability of seniors that may make them reluctant to make commitments too far into the future. Even in the context of potential challenges, group work with older adults can be extremely rewarding for both the members and the facilitator. As Survivors' social circles diminish, the structure of a new group can provide both specific thematic benefits and a supported opportunity to socialize and form new friendships.

Café Europa and Informal Groups

"Café Europa" is a program that exists in various formats around the world. Agencies bring various Survivors together on a regular basis (usually monthly) to attend a social function. Since time has diminished the social circles of so many Survivors, an opportunity to "meet, greet and visit" with people of similar backgrounds has proven very popular. Coffee and refreshments are often associated with pleasurable pre-War and post-War memories of cooking, socializing and homemaking. Across North America and Europe, the Café Europa concept has grown to include entertainment, both home-grown and professional, member-led planning and, best of all, the creation of new and happy memories. These programs can range from inexpensive and simple, where participants contribute a few dollars to cover basic costs in a community hall, to more lavish simcha-like gatherings (large, happy celebrations). Some programs seat people by country of origin, some provide events for an ethno-specific group, and some are open to whoever arrives.

Formal Groups

A formal group can be created to establish an identity and purpose that is meaningful for its members. A group can offer Survivors an opportunity to meet each other; to form friendships based on similar past traumas and current lifestyles, and hopefully, to develop a network of support among members as they cope with aging. The notion of a "therapeutic group" is foreign to many Survivors, but the ability to form a strong mutual aid and support groups can develop naturally with appropriate supports.

Participants can form strong bonds, become mutually supportive, and demonstrate reciprocity and respect of individuality. They can share their stories, their fears, their memories and their strengths. The participants can come together as a group and maintain mutually supportive relationships outside of the formal group structure. As Survivors, they can listen to each other with an acute understanding that no one else can offer, and this commonality can extend to current challenges. They can be there for each other for both sickness and health, and the bonds that develop will serve them well. Over the years, in order to both sustain interest and morale, the group can take on specific projects.

A Memory Quilt: A Group Project

The Terrace Holocaust Survivors' Group was created at Baycrest Centre to offer Survivors who reside in a supported living environment an opportunity to come together and share their stories, their frustrations and their coping mechanisms. The Group provides a supportive setting to discuss difficult issues, current challenges, share pleasures and be with others who understand each other's war experiences. In order to recognize the trauma and the pain that its members have endured, and also to celebrate members' resiliency, the Group has taken on a range of creative projects.

The actual production of the Survivors' Quilt was based on a photo transfer technique that allowed high-quality photocopying of images onto fabric. Discussions centered on which members had photos, who had other suitable memorabilia, what was suitable memorabilia, who could still sew and who would be interested and capable of tackling a major craft project. The reality was that the frail and elderly group members were unable to handle a project of such magnitude. Skilled volunteers supported the successful completion. The process, the interaction with the volunteers and the beautiful outcome was a great source of pride for each of the Survivors involved.

Initially there was reticence to participate a project that required photos. Very few emerged intact from the War, and those that did were extremely precious to their owners. Even discussions about what photographs were available triggered memories of destruction and reminded Group members of the enormity of their losses. The leader established that each participant had at least one pre-War photograph, and they all had photos which recorded the progression of their post-War lives. Whether they evoked memories of better times and provided comfort, or were harsh reminders of multiple losses, each photo was cherished.

The role of both pre- and post War photographs and other important memorabilia was discussed in the group. Members talked about what images would provide an appropriate representation. The notion of focused, therapeutic intervention, coupled with an opportunity to produce a narrative which the client can share with his/her community, is a "good fit" with groups of aging Survivors. While the quilt was the product, the functional focus, the therapeutic elements of various group discussions elicited new disclosures in a safe and supportive environment. The deconstruction of personal narratives, supported by visual aids, allowed group members to reframe their traumatic memories and stories and to express them in a positive and rewarding context.

Since each member was allotted a 12.5"x12.5" square, there would be a personalized approach to composition and design. The emotionally (and therefore physically) draining task of identifying and describing treasured photos was one that the leaders felt was best done separately in the comfort of individual apartments. Within the Group, the group leader discussed the quilt, especially its therapeutic and design potential, and helped members respond to various issues that emerged. Outside Group meetings, members were asked to look through their own possessions and select what might be appropriate for the quilt. Then, with the volunteer, they considered all the possible items, and chose appropriate pieces. There were discussions about colour and design as they related to each items and to the Survivor's own personality and taste.

The resulting Memory Quilt is over 1ten feet wide and five feet high, and each of the 18 residents helped produce a square. Each square forms a collage of photos, colours, patterns and documents, all transferred onto fabric and stitched together with other Survivors' squares, forming a testament to human resilience and courage. Mirroring the strength and mutual benefits to be found in group work, the quilt took individual contributions, and brought them together to create a new entity. In this case, the sum is indeed greater than the parts! There were both clinical and organizational challenges in working on such a large project with concurrent group and individual components, but they somehow paralleled the creation of a quilt, where individual bits and pieces are collected to form a new whole.

The Group created the Memory Quilt to warm and comfort the soul, mixing images of murdered family members and destroyed homes with the joy of beaming faces at children's weddings, the faces of grandchildren holding their babies. Each square represents a visual and narrative miracle, a poignant combination of past, present and future that represents a personal life statement containing that contains universal truths. The finished Quilt has an impact that transcends both art and craft, making a unique contribution to Holocaust expression. The Group made a Quilt that honours the victims, gives solace to the creators and hangs as a legacy for future generations.

"This Quilt is about us, and it is about our life. It may look just like material or cloth to you, but to us, it is everything. Now this Quilt can tell the stories, the stories that are important -- -not just our lives, but Life for the World". Fela Karmiol, member of the Terrace Survivors' Group

The Collective Poem: A Group Activity

Throughout this manual, the reader will find poems from the Terrace Holocaust Survivors Group. The formula for creating these Collective Poems evolved during the Group meetings. When Group members speak with their heads, the result is conversation; when they speak from their hearts, the result is poetry. When the Survivors' Group meets and they speak of their pain and their triumphs, it is always poetry.

A Collective Poem is facilitated, compiled and edited by the Group leader. The vehicle of poetry enables the Group to express their thoughts, share their feelings and support each other as they deal with difficult memories. Creating these poems can be a focal point for the Group over many weeks or months.

The leader takes the notes or tapes of a particular meeting, then collates and edits verbatim sentences from the participants, piecing them together to form the final product. The members consider the finished poem at the start of the next meeting and are encouraged to clarify, elaborate or change only their individual contribution. The Group as a whole evaluates the overall result, before giving final approval. The leader developed this technique out of her need to focus the discussion, and the members responded with an enthusiasm and optimism that rejuvenated everyone involved. While each member's story and experience is totally unique, the trauma and pain are shared by all. So are feelings of satisfaction and pride. One of the Group's earlier poems discusses the Group itself:

Yom Ha Shoah Ceremony

Yom Ha Shoah, the Holocaust Memorial Ceremony, is an important observance that recognizes Survivors and allows family, friends and caregivers to support them through their annual mourning ritual. Survivors and agencies and facilities that care for them should consider this Ceremony an integral part of the annual cycle of observances. Yom Ha Shoah gives Survivors and their families the opportunity to say "Kaddish," the Jewish prayer that is recited on the anniversary of the loved one's death. Since many Survivors do not know precise dates of their relatives' deaths, Yom Ha Shoah has been designated an official date of mourning for the millions murdered.

Ceremonies should be led by Survivors whenever possible, and customized to participants' needs. This is not an educational event but an extremely personal and difficult one for each Survivor. The concept of a public Ceremony as opposed to private prayer has grown. It is one way the community lets Survivors know that their pain and loss are recognized and also shared. The Ceremony is also an opportunity to celebrate the lives of the Survivors - both the fact that they survived the Holocaust, and the challenges they faced and overcame post-War.

Annual Yom Ha Shoah Ceremonies can provide a suitable service for all interested residents, family members, community and staff in a long-term care setting. Survivors are both encouraged and assisted where necessary to light memorial candles for lost family members. Prayers and recitations are given in several languages. Within residential areas, closed circuit television can broadcast the Ceremony to those who are bedridden or otherwise unable to leave home.

Supporting the grieving process and grieving itself are both challenging and potentially healing acts. A community Ceremony can take place in a community or seniors' centre. The event may be advertised as "open to the public." In such settings, Survivors are generally less frail and are able to direct both the content and the format of the service. In some centers, local school children participate. Such an event can give Survivors a sense of continuity, the comforting awareness that a new generation will remember the legacy of the Holocaust. Children represent hope for a better future, and their presence can give a great deal of pleasure and comfort.

Holocaust Survivors in Rehabilitation Programs

Peggy Arden, MSW, Baycrest Hospital, Rehab. Unit

Holocaust Survivors are a diverse group. Their common bond is that of catastrophic trauma, multiple losses and pain. Their experiences on the Rehabilitation unit have been influenced by their diversity as well as by their shared trauma.

Our in-patient Rehabilitation Unit is located in within Baycrest Centre's geriatric hospital facility. It is a limited stay, 24-bed unit, designed for people aged 55 and over who require in-patient therapy as a result of fractures, stroke and other conditions. The purpose of the Rehabilitation Unit "is to assist each patient in attaining his/her maximum potential in physical, communicative and cognitive functioning, while addressing emotional, social and spiritual needs". On average a significant number of patients are Holocaust Survivors.

People in hospital typically have little to do except try and recover. There is plenty of time to reflect on the past. For Survivors who have led busy, active lives and managed to push Holocaust memories as far away as possible, being hospitalized means they have time to think and remember. Buried memories of traumatic events, including feelings of loss and grief, may surface, interfering with the recovery process.

During the Holocaust, any sign of illness, weakness or vulnerability usually meant an automatic death sentence. Hospitalization after an injury or illness can re-awaken fears of being helpless and powerless. These feelings can impede rehabilitation and delay plans for discharge from hospital. But our experience has also shown that some Holocaust Survivors, for whom weakness is not an option, actual recover more quickly because they are so determined not to be sick. Problems occur when, despite their strong motivation and best efforts, recovery is slow and more limited than the patient would wish. At this point, it's not unusual for depression to set in.

Some children of Survivors view their parents as immortal because, after all, they survived the Holocaust. Family members may have difficulty accepting that an elderly parent or grandparent suddenly needs their help. Some children of Survivors find it difficult to respond to their parents' needs because of their own accumulated feelings of anger. Such feelings can come from the many stresses and enormous responsibilities associated with being a child of Survivors.

Interactions between Survivor parents and their adult children are often characterized by over-involvement, lack of boundaries and difficulties with separation. Such feelings may be acted out when a Survivor parent enters hospital.

Empathy and consistent contact are helpful in gaining the trust of Survivors and their families. Staff need to become familiar with potential triggers which cause painful memories of the Holocaust to re-surface.

Health care workers often have to respond to concerns of the Survivors' children. Some adult children who are themselves experiencing fear, mistrust or depression related to their parent's situation may bombard staff with questions. There may be suggestions that "not enough is being done." Such hostile reactions from Survivors' families are best met with calm explanations. This reaction is more likely to allay the person's fears and prevent them from making unrealistic demands.

Group work can also be a good modality for creating supportive relationships among hospitalized Survivors and their families. Members of the group can serve as substitutes for extended families.

Case Study: Mrs. M.

Mrs. M., an 80 year-old widow, was admitted for rehabilitation following a fall which resulted in several compression fractures. She had a previous diagnosis of depression. On admission Mrs. M was able to get in and out of bed with supervision. However a few weeks later, she reported increased pain in her back and hip, which made her unable to participate in therapy because she had "too much pain." She was also reluctant to get up for meals. At times she would crawl out of bed and walk to the bathroom and was occasionally found crawling under the bed. She was clearly depressed, and so a psychiatry referral was made.

Mrs. M. was born in Yugoslavia. She reported verbal and physical abuse in her childhood. Her mother was fixated on bowel movements and started giving her daughter enemas when Mrs. M. was eight years old. During the War, she was taken to Auschwitz concentration camp. She explained that she was chosen as a worker because she was physically strong.

The Nazis killed her entire family of origin, along with Mrs. M.'s husband and their nine year-old son. Following the War she remarried another Holocaust Survivor. Her only son described his parents' marriage as strained. In 1964, her husband committed suicide. Mrs. M.'s son, a schoolteacher, was married to a social worker and he and his wife were attentive to Mrs. M. However, her son stated that no matter how much attention he paid his to mother, it was never enough. This left him feeling powerless and inadequate.

The Rehab staff also felt helpless in trying to help Mrs. M. It was important for them to know her background so they could empathize and better understand her behaviour. Social work and Psychiatry staff shared information about her personal and family history with members of the Rehab team.

Mrs. M. stated that being in the hospital was like being back in Auschwitz. Her loss of health was very frightening to her, because she believed it was her physical strength that kept her alive during the Holocaust. Mrs. M's difficult life before the War also influenced her coping ability at times of crisis, including illness and hospitalization. Staff were advised to give Mrs. M support using a consistent approach. Nurses went into her room every hour. This reduced her anxiety, which was caused in part by fears that she was being forgotten. Despite the best efforts of the Rehabilitation team, it was decided that Mrs. M. should be transferred to an in-patient psychiatry bed. Her stay there proved most beneficial.

Social work and Psychiatry team members met with Mrs. M.'s son and daughter-in-law to provide education about the reasons for her behaviour and also to offer support. Social work also helped Mrs. M.'s son plan for his mother's eventual discharge.

Case Study: Mr. W

Mr. W., a 75 year-old married man, had a stroke and was admitted to the hospital for rehabilitation. He found hospitalization very difficult. He had been totally independent prior to his illness, although according to his wife, he had suffered with untreated depression for years.

After he was admitted, Mr. W stated that some hospital staff reminded him of the Nazis. He also said that he felt out of control and wanted to be independent. At the same time, he demanded that his wife do everything for him. For example, he insisted that his she sleep in the hospital, and she agreed that her husband needed her to be there. Rehab staff arranged for Mrs. W. to stay with him overnight. As long as Mr. W. was in a private room, the arrangement worked well. However, when he moved to a ward room, the situation became challenging for his wife and for other male patients in the ward.

Mr. W. had difficulty adjusting to hospital routines, which were quite different from those at home. Before his stroke, he never ate breakfast and remained in his pajamas all day, unless he planned to go out. Rehab staff accommodated him by arranging to have his breakfast served much later than usual. However, they encouraged him to get dressed, pointing out that whenever he left his room, this was just like "going out" of his house.

Mr. W. was born in Poland to a highly Orthodox Jewish family. His father was a Rabbi who came from several generations of Rabbis, and he fully expected all his sons to become Rabbis, too. Mr. W. did not choose to become a Rabbi. His father told him, "Either you daven (pray) or you don't get breakfast." Mr. W refused to daven and didn't eat breakfast again for many decades.

Mr. W.'s father died before the War broke out in Europe. The Nazis incarcerated Mr. W. in a work camp when he was 16 years old. He escaped with his two older brothers, and together they survived by hiding in the woods. Mr. W. witnessed the beating and killing of his sister by the Nazis. He later found out that his mother had died in concentration camp. Towards the end of the War, his eldest brother was shot.

Mr. W had been training to become a dentist before the Nazis took over. After he emigrated to Canada, he earned a living as a factory worker. In 1957, he married his wife, who was 13 years younger and whose Wartime experience had been quite different than his own.

Mrs. W. was born in Italy. Her father, a native of France, died during the War. Mrs. W. would tell how her mother pleaded with the Italian government not to send the family to a concentration camp. She said that because her mother had been born in Italy, the family was spared this fate.

Mr. and Mrs. W. have had a close relationship, and she said she always saw him as a father figure. Recently, Mrs. W. has faced some health challenges of her own.

When Mr. W. was admitted, both he and his wife were adamant that none of their five daughters should be contacted or involved in decision-making. Much friction was reported between the eldest single daughter, who had rebelled against her father's authority, and her four siblings. The three married daughters appeared to have "on again, off again" relationships with their father. The fifth daughter, also single appeared to have the closest relationship with her parents. None of Mr. W.'s daughters contacted social work staff during his hospital stay.

Members of the Rehab team were informed about Mr. W's history by Social work staff and Nursing staff. The goal was to help team members understand Mr. W's behaviour and family dynamics. Staff tried to accommodate hospital routines to meet Mr. W's needs. Mr. and Mrs. W. attended a Stroke Group for patients and families where they were offered education and support. A social worker met weekly with Mrs. W. who was finding it difficult to cope with her husband's behaviour and his many demands on her. Joint sessions were also held with Mr. and Mrs. W. to help them discuss their current situation and plan for the future.

Eventually, Mr. W. was discharged home. Renovations were planned to make his house more accessible, including the building of a ramp. Home care was provided, and Mrs. W planned to hire private help. Outpatient physiotherapy was offered at Mr. W.'s home. A social work referral was made on discharge.

Issues Raised in Case Study

Both case histories serve to illustrate certain themes. Their pre-War lives seemed to have had an impact on how both Mrs. M. and Mr. W. coped with the horrible trauma of the Holocaust. Both had suffered from depression prior to hospitalization. Both found that being hospitalized for a serious illness challenged their existing abilities to cope with problems.

Once Rehab staff understood the meaning of these patients' behaviour and what triggers were involved, they were able to adapt their own behaviours and look for helping strategies that would produce a better outcome.

A clear theme apparent in both these cases is how great a premium Holocaust Survivors place on self sufficient and strong. During the War, any illness or infirmity was likely to result in death. Staying healthy meant you might stay alive.

In both cases, the patient's family members felt helpless and powerless to "save" the Survivor from further suffering. These family members needed understanding, support and reassurance from staff that everyone involved was doing the best they could.

The motivation among Survivors to stay healthy and independent "at all costs" can be an advantage when an elderly person is trying to recover from medical illness, injury or surgery. It is extremely important that rehabilitation staff realize just how much recovery means for these patients.

Tips for Working with Survivors in Rehabilitation Units

Be aware of the patient's history, including whether he or she is a Holocaust Survivor. If a patient is Jewish, was born in Europe and came to Canada after 1945, this person is probably a Survivor.

Staff needs to be aware of the patient's experiences during the Holocaust which can help them understand certain behaviours. Be aware of the many environmental triggers that can cause traumatic memories to re-surface during a hospital stay (see section on Triggers).

Be aware that hospitalization and illness can re-awaken Holocaust-related feelings of helplessness and powerlessness. While some Survivors become quite depressed, others show amazing determination to recover.

Empathy and consistent contact are helpful in gaining the trust of Survivors and their families.

Sometimes children of Survivors displace their strong emotional feelings (anger, fear, sadness) onto staff. This can come in the form of unrealistic demands. It is best for staff to respond with calm explanation rather than with irritation.

Staff should be flexible with hospital routines in order to accommodate the Survivor's needs.

Staff should understand why health and independence are so important to hospitalized Survivors.

Education/Support groups can be beneficial for Survivors and their families, since there are usually few extended family members to provide informal supports.

The Personal Care Worker Perspective

The Personal Care Worker (PCW) is responsible for providing basic nursing care, doing household tasks and lending psychosocial support appropriate to their level of knowledge, skill and judgment. Opportunities for PCWs exist both in the community and within health care facilities where they are an integral part of the multidisciplinary team. Indeed, PCWs are often the ones who spend the most time with the client. Because of this, it is important that staffs that assume this responsibility are properly trained. They can be instrumental in helping clients who are Survivors of the Holocaust cope with the effects of aging, injury and/or illness.

Mr. J.'s Story

Mr. J. was born in Poland to a very religious family. As a teenager, he rebelled and ran away to Vienna to study with young intellectuals who were exploring the field of psychiatry. There he met and married a fellow psychiatrist.

When the War broke out, Mr. and Mrs. J. were both deported to Auschwitz concentration camp, along with their infant son. The baby died in the cattle car of the train that was transporting Jews the Auschwitz. Miraculously, both Mr. and Mrs. J. survived the camps, although after the War, neither one was able to find a single living relative who had also survived.

The couple emigrated to Israel and eventually came to Canada where Mr. J. worked as a psychologist. Mrs. J. never regained her health and was unable to have any more children. The absence of family was an ongoing sadness for both of them, and as Mr. J. explains, unhappy shadows of the past were always present. Mrs. J. was never able to work and, with age, became very frail. Mr. J. hired a personal care worker and the two of them cared for Mrs. J. at home until she passed away at the age of 60.

The personal care worker and her family "adopted" Mr. J., and he became the family's surrogate grandfather. He continued to see patients until the age of 65, when he moved into a retirement home. In the home, he was dependent on his fellow residents and on staff for his social connections and emotional support. He continues to be invited by his adopted family to share holidays and dinners, but since his wife's death he says he feels very much alone in the world.

The Institutional Perspective

Helen Taylor RN, Coordinator, Personal Support Worker Program, Baycrest Centre

Personal Care Workers (PCWs) may come in contact with Holocaust Survivors during the course of their career. For this reason, it is important that they understand the personal and medical histories of these clients. This is vital because of the many triggers within the institutional environment that can seriously upset elderly Survivors.

The client's personal history has a huge impact on the design of the care plan. The person's current medical condition and cognitive status are also factors to be considered.

For example, a Survivor who is being helped to shower may become extremely resistant. Inmates of concentration camps like Auschwitz were murdered in specially designed shower rooms where lethal gas was pumped in rather than water. Some Survivors, particularly if they are cognitively impaired, may be terrified that is happening again. But by giving clear explanations in a calm voice, the PCW can help make the shower experience less threatening. However, with a cognitive impaired client, the fear of showering may be too great. In this case, an alternative - a tub bath, washing in front of the sink - may be required.

Because of their War-time experiences, Survivors may respond to a variety of triggers. Some react negatively to loud noises (including thunder) or to authoritative personalities (people with loud voices or who wear uniforms). They are often afraid or suspicious of medical personnel and procedures. Their Holocaust experiences may have left them with fears of the dark or a fear of dogs (used by Nazi police and solders). They may believe their food or medication is somehow being poisoned. They may have special anxiety about food (there can never be enough) and express unwarranted fears about their family's well-being as well, which causes stress for themselves and family members.

However it is important to remember that Survivors are individuals who may or may not react in a predictable manner. Like all of us, Survivors are unique individuals and PCWs must take the time to understand how various aspects of care will affect their clients. affects each client.

Case study: Mrs. B.

Mrs. B., now age 93, moved to Canada after being liberated from a German concentration camp at the end of the War. Very little is known about her past, since she has no living relatives and is cognitively impaired. However, there are time when she feels comfortable enough with her health care provider to mention her long-dead father. She might say that he will soon be coming to take her dancing or that he is on his way home and will need his dinner. Mrs. B. feels she must be clean and dressed at all times so that she will be ready when he comes. It's also important that there be food on hand to serve him. Mrs. B.'s eyes rarely shine, but they always shine when she talks about her father.

Issues Raised in Case Study

Although her medical problems were stable, the client had two issues that needed to be addressed.

Malnutrition Mrs. B. was not interested in food for herself. She would take a few bites and refuse more. It was discovered that she was hoarding food for her father's imagined arrival. She would hide most of her own meal in her bedside dresser. Mrs. B. needs close supervision during mealtime and snacks. The PCW must stay with her, cut up her sandwiches and meat and encourage her to eat all of her food. While assisting her with meals, the PCW should talk about pleasant things - like her love music - and praise her for eating. Most of the time she enjoys talking about her childhood. She should be given this opportunity whenever possible.

Restlessness and Agitation Mrs. B. is usually very quiet in her bed or chair, but at times she becomes agitated, yelling and grabbing at staff. If she finds herself in an unexpected situation, she becomes upset and agitated. The PCW should let her know in a calm, pleasant voice what is happening at any given time. She should be allowed to assist in her personal care as much as possible. For example, if she needs her incontinence wear changed; tell her what you are going to do. Give her time to turn from side to side on the bed herself, rather than pulling into position. Mrs.B. often bangs on her bedside table. This is her way of "playing the piano," something that brings her much joy. Because she has a private room, allow her to continue this behaviour at appropriate times.

Issues for Consideration

Coping with Death and Dying: The PCW should allow Mrs. B. to verbalize if possible and offer comfort and reassurance. Be sure that the client receives optimal physical care such as frequent turning and positioning (depending on medical condition). Mrs. B. has periods of depression when she prays for death. Give her privacy and allow her to express herself in an emotionally safe neutral environment.

Emergency Illness: PCWs working in a care facility should report any changes in their clients to the nurse. Always comfort and reassure the client in a calm manner.

Impact of Chronic Illness: Allow your client to verbalize and offer reassurance. Your client may want more information about his or her illness. Discuss this request with the family and members of the care team. Mrs. B often becomes frustrated and angry due to her physical limitations. Allow enough time for her to perform simple tasks and assist her only when necessary.

Impact of Long Term Care: Allow for a period of adjustment. Provide encouragement and support. Mrs. B enjoys group activities such as recreational therapy and music therapy. Be sure to include this in her care plan. Religious events are also important to her, and her attendance must be a priority.

Impact of Acute Illness and Hospitalization: PCWs must strive to meet all of their clients' physical and psychosocial needs within their scope of care.

Impact on Family: Allow family to verbalize their fears and concerns. Include them in decision-making and hands-on care if they desire to be involved. Although Mrs. B does not have any family or visitors, she enjoys reminiscing about them. Offer a comfortable environment so she can talk about her childhood memories and actively participate in the conversation.

Personal Impact of Caring for Survivor: Often staff is unaware of how they are being affected by the physical and emotional demands of caring for a very needy or frail Survivor in long-term care. PCWs should actively participate in client conferences. If they are feeling stress, they should ask for assistance/support from other members of the multidisciplinary team.

Tips for Personal Care Workers

- Assess the Survivor's' behaviour keeping his/her history in mind.
- Provide a calm, pleasant environment.
- If the Survivor is resistant to certain types of care, revise your care plan.
- Allow Survivors to verbalize about their past, present and future.
- Be an active listener.
- You many hear upsetting stories. It is okay to be upset yourself. It is not okay that your emotions further upset your client. Rather than saying "I feel terrible too", you might say, "That must have been terrible for you."
- Encourage your client's participation in group activities - games, social, physical, intellectual, religious activities.
- Encourage family participation in client's care/activities.

- Make efforts to explore the memories, people and events in your client's life that create a feeling of pleasure or peace.

The Community Perspective

Arnold Foss, BSW, RSW, Circle of Care and Bluma Heimlich, MSW, RSW

The Personal Care Worker (PCW) is invaluable in supporting individuals to remain independent in their own homes. Working collaboratively with individual clients, family members and community professionals, the PCW assumes a unique role in providing assistance with personal care, managing household tasks and giving other caregivers periods of respite. As well, they provide much needed companionship and emotional support.

When working with Survivors, it is imperative to understand that people respond to traumatic life events in different ways. While it is important to understand that individual Survivors experienced extreme trauma during the Holocaust, it is equally important to realize that individual post-War circumstances will impact on how they respond to home support today.

For some Survivors, adapting to the aging process can be especially difficult. A decline in physical health may restrict and lead to disengagement from activities. Present life stressors - retirement, the death of or separation from a spouse or adult child, illness, the need to live on a fixed income - may bring about feelings of loss, dependency and vulnerability related to their early life experiences. During the Holocaust, Survivors knew that their health and being able to look after themselves were vital for survival. The PCW must be aware that Survivors can respond negatively to their presence because such clients have such a deep-seated, powerful desire to remain independent.

The PCW should be aware of that certain everyday sights, sounds and events might trigger a specific War-related flashback or reaction. This may be the source of a client's extreme or unusual reaction, and can provider clues about possible interventions. Survivors may exhibit different - and sometimes surprising - coping mechanisms that helped them survive in the past. They may continue to use the same strategies.

It is essential that the PCW respond in a sensitive and understanding manner and try not to take unusual reactions personally. If the client's reactions become extremely difficult, PCWs need a safe outlet to express their own feelings. They should be able to discuss concerns and questions with their supervisor. If they have specific questions that relate to better client care, they should discuss these with their clients where possible, or family members.

Case Study

Mrs. G. was a child during the Holocaust and was traumatized by her experiences, which included deportation, loss of home and family, and placement in a concentration camp. Mrs. G,'s lives in her own home and has no surviving relatives.

She suffers from nightmares, a sleep disorder and frequent depressions. She is also affected by severe multiple sclerosis and fights with every bit of strength not to give in to her disease. Despite her daily struggles, she refuses to consider placement. Her home is synonymous with her freedom. The experience of moving into a long-term facility would remind her of how her life was disrupted in childhood, how she was uprooted, dislocated and incarcerated.

Mrs. G. has no family. Although it has been very difficult for her, she has grown to trust her Personal Care Worker and accepts assistance. Her caregiver understands Mrs. G.'s history and her need to be independent. She pays extra attention to how she provides care and has learned to avoid or control certain triggers, which cause painful memories.

Frequently, especially when Mrs. G. is depressed, she will not allow the Personal Care Worker to enter the apartment. Often her nightmares are so vivid that she will not even answer the telephone or door, afraid that "someone will find me."

Mrs. G.'s life in old age reflects the phenomenon of "re-traumatization." This occurs when early life traumas continues to haunt an individual over many years. Her caregiver is doing all she can to allow Mrs. G. to remain in her own home.

Issues Raised in Case Study

No living family

One of the few contacts that Mrs. G. has is her PCW. She should be available to listen to her client when problems arise. It's important for the PCW to encourage Mrs. G. in making day-to-day decisions about her activities and her care, but be prepared to make suggestions.

Fear of being placed in a long-term care facility Because of Mrs. G.'s history of dislocation and incarceration, she has a powerful need to remain independent and feel in control of her environment. Moving to a long-term care facility would remind her of her incarceration. The PCW should encourage her client's independence. At the same time, the PCW must be realistic about the client's situation and evaluate it on an ongoing basis.

Trust issues

For Mrs. G. to maintain her independence, she must be able to trust those who are helping her. The PCW has to earn that trust by providing a safe environment, where Mrs. G. feels free to verbalize her fears. If the client feels comfortable, she is more likely to accept suggestions and help. However, in this case, the PCW should wait to be asked for her advice before offering it.

Difficulty in accepting assistance

Having survived the Holocaust, Mrs. G. felt should must always fend for herself. As her disease progressed, she needed more and more help. The PCW must encourage independence. But when the client does require assistance, it's important that such help not be imposed on her. Instead, help should be given when it is requested. The only exception to the rule is when the PCW feels Mrs. G.'s safety is at risk.

Reliving memories of the past

The PCW must recognize the source of Mrs. G.'s nightmares and sleep problems and do all she can to comfort her client. She should try not to take the client's refusal to let her into the home as a personal affront.

Tips for the Personal Care Worker

Whenever possible, support the client's need to be independent. Try not to perform any task that the client might be able to do herself. Or else, try to do such tasks with together. Focus on the strengths as well as the needs of the Survivor.

Pay extra attention to how care is given. Allow the client to lead the way. Ask permission before providing care or doing a task. Aim for an informal method of providing service, rather than a rigid by-the-book style.

Considering how frightening it must be to need help and to have a stranger come into your home. Take things slowly at first. A calm, caring response to negative behaviour can only help. With the help of the supervisor, the PCW can devise strategies that foster trust. If a client behaves in a "difficult" or uncooperative manner, it is important for the PCW to identify and try to understand this behaviour. Such information should be shared with the supervisor.

Learn what triggers difficult memories for your client. Consider the client's life experiences when establishing any type of care plan.

Talk about War-time experiences only if the Survivor raises them. The trauma of the Holocaust has remained central in the lives of Survivors. Even though some have not talked about their experiences in the concentration camps, in hiding, while living in the woods or being on the run, these memories and the feelings they create are ever present. Listen to these stories if the client is willing to share them. Being heard and acknowledged is important for some Survivors. Remember that aging and illness are key transitions and provide opportunities for sharing. Sharing memories and stories may be a vital way for clients to connect to their Personal Care Workers.

Client Assessment: Data Collection

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When Personal Care Workers enter a client's home, they also enter into a helping relationship which is a vital component of overall care. To form a quality relationship, the PCW must understand her client. An individual's personal history is important as it adds to:

- the total assessment,
- the overall cluster of data necessary for holistic care
- the ability to identify possible needs
- the contribution to a nursing diagnosis (problem)
- the setting of goals
- the prioritization of these goals
- the development of appropriate interventions
- the ability to help a family members/caregivers/health care team predict possible outcomes

The importance of information and background provided by the client cannot be underestimated. The meaning of this information should never be assumed until facts are validated with the individual and/or family/significant others.

Holocaust Survivors may be reluctant to share their history, and the PCW should not push or make the client feel obligated to answer questions. The most effective way to obtain personal history is through conversation, asking questions naturally, whenever the opportunity arises and when client seems most comfortable. When a client expresses hesitation or refuses to answer, this should be respected. Some Survivors are very cautious about divulging personal histories. Others find this comforting. PCW s should always take their cues from their clients.

A personal history would include:

- cultural background and personal identity
- educational experiences
- areas of interest
- skills and talents (strengths)
- areas of weakness or lack of skill
- life events that have affected their life choices
- support circle/family and significant others
- meaning which the person gives to their support circle/family relationships.
- philosophy of life focusing on specific issues that have an impact on care giving issues such as trust, control of the environment, privacy, territory
- health history-state of wellness throughout life, including medical history: allergies, illnesses and treatments
- Why is it important for the PCW to consider these factors when caring for an individual, group or family? Such information helps care providers to:
- identify needs, preferences, strengths and weaknesses and include them in the plan of care
- anticipate needs prior to and during care
- build on strengths and support weaknesses
- support independence and choice.

Understanding "triggers"

These are ideas, objects or activities which cause Survivors to recall events over the course of their lives - including traumas which they experienced during the Holocaust (see section on Triggers) Such memories of deprivation, starvation, torture and confinement may lead to specific reactions or responses during some current activity or interaction.

The concept of triggers can be applied to every client, not just to Survivors of the Holocaust or some other horrific event. As PCWs become more familiar with their clients, they can do much to curtail or prevent these associations, helping to ensure a positive outcome and a better quality of life.

The Housekeeping and Maintenance Perspective

Housekeepers

The role of housekeepers is crucial to residents of health care and long-term care facilities. A clean and orderly personal space is important in helping Survivors feel comfortable within their environment. As Housekeepers are continually moving in and out of residents' rooms, they often form close and meaningful relationships. In some instances they may have as much direct contact with residents as members of the care team or even some relatives.

Tips for Housekeepers

Always introduce yourself by name. It is important that the residents understand you are a person who contributes to their well-being. If the resident has a memory problem, you may have to introduce yourself on a regular basis.

Get to know the residents in your area and be sensitive to what might trigger Holocaust memories.

If you are working in a new area, ask staff if there is anything you should know in terms of fears or triggers for any Survivors in that area.

Walk into rooms quietly and explain what you are there to do.

If there are noises or smells associated with your tasks, let residents know what they are and how long it will take you to complete the task.

If you are operating loud machinery, explain that it will be noisy for awhile. Try to move slowly and remain as far away from residents as possible.

Managers should try to keep housekeeping staff in the same area so they become familiar faces to the residents.

Let nurses know if a resident needs something that you cannot do for them.

Even if the resident cannot speak or seems too ill to be aware of you, these tips still apply.

Talk to residents, smile and be friendly and courteous.

Maintenance Staff

Staff who maintains the physical plant in a long-term care facility may come in contact with Survivors. Whether repairing, painting or maintaining something in the resident's room or in a common area, your presence will be noted. Each time you are there, the residents should always be told who you are, why you are there and what you are doing.

Tips for Maintenance Staff

If you are in someone's room, always introduce yourself by name. It is important that the residents understand you are a person who contributes to their well-being. If the resident has a memory problem, you may have to introduce yourself each time you are on the unit.

Tuck large key rings into your pocket so that the noise of the keys jingling will not be disruptive.

If you wear steel-toed work shoes, you should choose a type with rubber on the bottom. This will prevent you from making a loud noise when you walk on an uncarpeted hallway.

When carrying a two-way radio, turn the volume down or else turn it off when you are working in a resident's room.

If you are working with large, heavy tools, leave them outside the resident's room at first. Go in and explain what you will be doing and describe the tool that you will be using and why. Then go outside and get the tool.

If you know you will be working in a particular area, tell nursing staff the day before so they can inform the residents that you are coming.

If residents are asleep, avoid startling them. Come back later if possible.

If a resident's door is closed, check with the nurse before knocking.

On locked units, always walk residents back to a nursing area before you leave. A locked door could be very triggering and make someone feel trapped or imprisoned. Gently guide the resident back to a safe area.

Remember to ventilate areas where you will be using materials that give off strong odours such as paints and cleaners. Such odours can have terrifying associations for Survivors. Use exhaust fans whenever possible.

Talk to residents, smile and be friendly and courteous.

Case Study: Mrs. Z

Mrs. Z. is a severely cognitively impaired Hungarian Holocaust survivor who doesn't speak or understand English or Yiddish and has a long-standing psychiatric history. Often, her reality is that she is living in the past during the time of the Holocaust.

Shortly after her admission to a long-term care facility, it became apparent that one of her coping mechanisms was to hoard. Not only did she hide food, she also collected cutlery after each meal (which she thought was valuable silver) to be used as currency if she needed to buy her way out of danger. Mrs. Z. hid these items where she thought they would never be found - inside the toilet tank. Once that was full, she began to put the cutlery down the toilet bowl. Nursing staff were aware of her activities and would try to clear the tank periodically, leaving only a few pieces of cutlery. When they weren't successful, flushing would cause a flood, and water would flow out of Mrs. Z's room into the hallway.

Maintenance and housekeeping staff were called on a regular basis to unplug the toilet and mop up the water. Certain staff called to assist with the clean-up did not understand the reasons for Mrs. Z.'s behaviour and reacted by becoming angry with her and with the nursing staff for allowing the behaviour to continue.

Issues raised in Case Study

- Validate the client's feelings and realize that Mrs. Z. is unable to distinguish past from present.
- Understand the client's past and the possible reasons for their behaviours.
- Discuss difficulties in communicating and reasoning with the client.
- Provide information and support to staff assigned to clean up
- Responding to the Issues Raised in the Case Study

It is vital to train housekeeping and maintenance staff, by acquainting them with the history of the Holocaust. This may help them understand certain behaviours exhibited by Survivor residents. In the case of Mrs. Z., the plumber should have been more sensitized to her past experiences. Then he might have reacted differently when called repeatedly to unplug her toilet and mop up flooding water.

Staff needs to be aware that such hoarding behaviour is not likely to change. They can then respond by developing strategies that allow her to continue to hoard safely for all concerned. This may include cleaning out her toilet more often, and if it does flood, to come in quietly and clean up the mess without making negative comments. It may be helpful for housekeeping and maintenance staff to seek peer support if they are faced with this kind of situation. A team approach involving maintenance, housekeeping and nursing staff would reduce the pressure for everyone involved in Mrs. Z.'s care.

Healthcare Managers and Supervisors

Pat Dickinson, Baycrest Centre

Managers play a vital role in ensuring high quality services for Holocaust Survivors by supporting and facilitating the work of staff who provide direct care. In order to provide optimum care, staff need to know their Manager also understands the unique needs of a patient group and supports their efforts to "go the extra mile."

The needs of staff vary according to their professional discipline, the background experience they bring to their role and their level of training. However, whether they are providing direct care as in nursing or social work or are providing services such as meal delivery, housekeeping, and so on, staff who work with Survivors will all face special challenges to some degree. A manager who is sensitive and responsive to these challenges can make a crucial difference to the effectiveness of their staff.

Benefits of providing good support for staff

For clients

Care will be more compassionate because staff better understand the traumas enormous challenges that Survivors have endured. Clients can feel more comfortable discussing these issues and the subsequent effects because staff are ready to deal with them.

Care will be more effective because staff have been well trained in the special needs of Survivors and how best to meet those needs.

Care will be individualized because staff will have the background to appreciate the diversity and unique needs of their clients.

- For staff

  With good support and training, staff feel:
- more comfortable discussing painful experiences with Survivors
- more confident in assessing Survivors' needs and developing strategies to meet these needs
- more competent when difficult situations arise
- more empowered to be proactive in working on behalf of Survivors and their families
- more fulfilled by providing optimum care to Survivors who lives remind us all of man's capacity for evil

For families

Families can be better educated about their relative's needs in the context of being a Survivor and thus better able to provide more sensitive support to their loved one.

Families will be better able to cope with difficult emotional situations when receiving comprehensive support.

Family members are helped to understand how living with a Survivor has affected them.

Families will learn more about how aging affects Survivors.

Families will have access to skilled guidance should new areas of communication open up between them and the Holocaust Survivor.

How the supervisor can provide effective staff support

Training and Education

It is ironic that most professional care providers do not receive training in the care of Survivors of genocide. This is a challenging area of practice that is supported by a rapidly growing body of literature. Even after initial orientation to the topic, and as circumstances change over time, it is vital that staff who come in regular contact with Survivors in long-term care have access to ongoing in-service training in the following areas:

Caring for Survivors: The special needs of Survivors; how caring for Survivors differs from caring for non-Survivors; situations which trigger emotional reactions; discussing Holocaust experiences; trauma and memory; the effects of aging on Survivors

Survivor programming and services: Types of programs and services that are of particular benefit to Survivors; how existing programs/services can be adapted for these clients; how to initiate, organize and deliver this type of programming

Delivery of treatment and services: How Survivors respond to various kinds of medical treatment and to health care professionals; how staff can adapt their techniques to treat Survivors

Families of Survivors: How to handle the special challenges of working with families of Survivors; how to work within the dynamics of a Survivor family which is usually very small and very protective; how to help families deal with institutionalization of an elderly Survivors and accept that others are now providing support; how to support families as they enter new and painful areas of discussion

Multicultural issues: For staff unfamiliar with Jewish culture, providing education about Jewish traditions and observances and the impact of the Holocaust; even staff who are Jewish may need additional education, including information about the language and/or customs of a particular ethnic or national group

Dealing with their own trauma: How working with Survivors might have an impact on staff who have endured trauma themselves

Issues within the Jewish community: Misconceptions about the needs of Survivors; intergenerational issues

Differences of nationality: Experiences can be very different for Survivors who came from western Europe vs. those who come from Poland

Issues of reparations/restitution: Which people in the Survivor community are receiving financial support, which people are not, how to apply

Issues of remembrance: Importance to Survivors and their families that younger generations do not forget what happened to them

Issues related to Israel: Its special meaning for Survivors

There are many methods for providing such support and education:

- this manual
- formal courses
- written materials (journals, books, newsletters)
- grand rounds
- presentations offered by on-site staff or guests
- conferences
- on-line resources (e-magazines, e-journals)

Emotional and Psychological Support

Working with aging Holocaust Survivors can be rewarding in many ways. Their courage, stamina and, in many cases, great compassion, are inspiring. However, listening to traumatic memories, dealing with behaviours and triggers, or possibly re-visiting one's own personal traumas can be extremely stressful on staff. There is the potential for physical exhaustion, depression, burnout, stress and a variety of other problems.

The Manager can help alleviate or prevent these by:

- being well-informed about the possible adverse effects on staff of long-term work with Holocaust Survivors
- being closely attuned to the well-being of staff and taking quick action should problems arise for them
- instituting supportive strategies including regular supervisory meetings, group discussions with peers, mentoring, team building activities, stress relief activities
- providing assistance when problems occur through employee assistance programs and counseling, adjusting schedules and workloads, rotation of duties, sabbaticals/leaves

Time and resources

Above all else, the supportive Manager recognizes that staff need time to process what they hear from clients, time to participate in in-service training and time to spend with their Survivor patients in order to provide quality care. Most (but not all) of the strategies for training, education and emotional support outlined above require additional staffing and resources. In addition to making sure there are funds to provide these opportunities, it is also essential that staff been given the time and the back-up to take part.

The Volunteer Perspective

Lesley Patterson, MSW, RSW Baycrest Centre

Volunteers can be found in a wide range of positions within many community and long-term care organizations. Their primary role is to help staff provide service, whether directly or in a supporting position. Committed volunteers enhance the services provided and can be useful in limitless ways, depending on the needs of the organization and on the leadership of professional staff who recruit, train and place volunteers. A successful volunteer program will meet the needs of the organization, the clients and also the volunteers.

Volunteers bring a sense of caring community to both residential and community settings. Through their work, they not only contribute vital service, they also provide significant reminders that older adults have not been forgotten and are respected and important people within our society. In the past, volunteers in geriatric settings typically worked in reception, at the information desk, and in the gift and coffee shops. Today volunteer roles have expanded into all areas of a community centre or facility.

In long-term care facilities volunteers often assist with recreational or social events, feeding and friendly visiting. In the community, they act as friendly visitors, provide phone reassurance to callers, and deliver meals-on-wheels. (Volunteers who go into people's homes to visit or provide service should be asked to undergo background checks by the local police department to ensure the safety of elderly community members.) Some areas of volunteer participation require little direct contact with clients - for example, clerical support, fundraising and marketing.

Volunteers in community settings have similar mandates, challenges and rewards. Community settings may be formal or very relaxed, but again, volunteers are crucial to the success of a range of programs and functions. The importance of informal interactions - for example, volunteers socializing in the lobby or directing families and friends to various locations - should not be minimized. Volunteers who provide such services should be recognized and supported.

Regardless of assignment, role or venue, the volunteer is representing an agency and the clients served. Each volunteer's role and position should involve a careful partnering of interest, skills, challenge and level of commitment required.

Whether they are placed in areas with high or low client contact, volunteers will always benefit from training and education. All volunteers within an organization should be offered the opportunity to learn and grow, both personally and within their chosen skill area. According to one organization that is very successful at retaining skilled and committed volunteers, community and long-term care organizations should "offer established volunteers continued in-service training. Often they can benefit from an in-service that is being offered for the staff, family members or possibly a training session geared towards the volunteer. The more you can give, the more you will get. This reinforces the reciprocal concept of determining what you and the facility can do for the volunteer." (Duncan, 1995)

Recruitment, training, placement and staff support, and appreciation are all part of a successful volunteer program. When the volunteers will be working with Holocaust Survivors there are factors to consider at every step:

Recruitment

The motivation to volunteer should be fully discussed during the recruitment phase. Why does this person want to volunteer? And why at your organization with your clients? Before placing a volunteer within your organization, it is helpful to know not only their skills but also their motivation, so you can make the best match between volunteer and task. (It is recommended that each volunteer provide you with at least one character reference.)

People volunteer for many reasons, some common and some very unique. They may want to achieve something positive, to give back to their community and/or to grow personally. In general, the typical volunteer has a sense of community responsibility and an interest in people.

Volunteering to Work with Holocaust Survivors

There are many reasons an individual might be interested in working with Survivors. As in any other area of volunteer recruitment and supervision, staff must consider and discuss the realities and potential of the particular assignment with each volunteer. For many of the reasons discussed in other sections, working with aging Survivors is challenging work, and volunteers should know what to expect. At the same time, they should understand that such work can also have many rewards.

When volunteers are exposed to Holocaust Survivors, they may feel inclined to somehow "protect" them from any further pain or distress. Indeed, this may be their strongest motivation for working with Survivors. But volunteers must be educated and supported so they do not promote overly dependent relationship with clients, or have difficulty following through with care routines that foster independence. Volunteers must also understand that each Survivor is unique, and that and some may resent "protection."

Training

Once you have determined what information is needed for volunteers to work effectively within your organization, an orientation or training program is designed. This training should help volunteers understand the meaning of the term "Holocaust."

One theory suggests there are three main areas or levels of "knowing" which should be addressed in volunteer training programs (Dancy & Wynn-Dancy, 1995)

Level One looks at the psychological and physical aspects of aging and addresses many of the myths, stereotypes and fears we have about getting old.

Level Two involves ways of getting to know clients as individuals who have their own histories, and preferences and so on.

Level Three looks at self-knowledge. "Volunteers bring their own values, attitudes, myths, beliefs and feelings that may or may not sharply contrast, or even clash, with those stored with the older adult clients." (Dancy, 1995)

These levels of knowing are important for volunteers who work with Holocaust Survivors. An ongoing review process should be conducted with the volunteer to ascertain that he or she is comfortable in working with potentially traumatized individuals. Training should be designed to provide volunteers an understanding of clients' medical status, how best to communicate with them, and how both environment and culture affect their behaviors.

Volunteers benefit from the same training that staff receives. Training modules should also cover any policies and procedures related to volunteering in the organization such as abuse policies, safety protocols and infection control, to name a few. As volunteers become more familiar with their tasks and their clients, they often become more interested in continuing education. Role-playing is often an effective technique to use with volunteers.

Volunteers must have a general understanding of the environmental "triggers" that could affect Survivors. Perhaps the most important aspect of their training would be to individualize the histories, expectations and personalities of all Survivors, understanding that each is a unique person with unique needs.

For example, some Survivors may be lonely and in search of social connection; others may simply want to know that someone is interested in them. Volunteers should understand that some Survivors may want to discuss their War-time experience, while others have no interest in doing so. Volunteers should always take their cues from the individual client. Where appropriate, staff should communicate to volunteers any relevant specifics. This will help the volunteer be more effective in developing a relationship with the client.

Placement

For best results, organizations should try to match the skills and abilities of the volunteer with the required tasks and client need. A clear understanding of the tasks and responsibilities of each volunteer job is important, and good communication is also essential. (Being able to talk a common language is always an asset.)

Staff should attempt to screen potential volunteers using a personal interview (including questions about reasons for volunteering) and by observing candidates during orientation and training. (Health screening and reference checks should also be part of the volunteer placement process.)

It is not unusual for the volunteer to start off with easier tasks until they feel more comfortable in their surroundings. At this point, they may have attained the comfort level needed to begin working with Holocaust Survivors. The opportunity to re-evaluate their placement is important even with long-term volunteers.

Volunteers often describe their job as being very rewarding. However those who genuinely care about their clients, including Survivors, face two major risks: they can become overwhelmed by the client's needs, and they may also be rejected at some point (Dancy & Wynn-Dancy, 1995). Volunteers may need support from staff members who work with or supervise them. Like paid staff members, volunteers can also benefit from debriefing and stress reduction strategies.

It is not unusual for a Holocaust Survivor to distrust strangers, and volunteers should be prepared, not only to earn the client's trust, but also to accept that rejection is a possibility. The role of "volunteer" might not be accepted or understood by the client. This may be due to early experiences with collaborators or sympathizers during the Holocaust. Volunteers should be cautioned to avoid behaviour that might trigger a negative reaction - for example, asking a lot of questions in an inquisitive style, or asking personal questions that might seem invasive to the client. Even if they understand that rejection stems from a previous experience and not necessarily from their own actions, the volunteer will appreciate support from colleagues and staff.

Staff Support to Volunteers

Staff who work with volunteers should remind volunteers about significant days (a happy or sad anniversary, for example) or changes (new medication, a new health problem) in individual clients. Staff are also responsible for ensuring that volunteers receive ongoing professional development in the area of aging Holocaust and trauma Survivors. The staff should become familiar with each volunteer's motivation and any pertinent background (is the volunteer himself or herself a Holocaust Survivor, a member of the Second Generation, or a survivor of some other trauma or oppression?). Staff must also ensure an appropriate level of supervision and provide positive reinforcement.

Historically, volunteers in hospitals and long-term care facilities were not there "full time," and were not regarded as part of the professional staff team. Because of this, they had less access to updates and reminders. More recently, volunteers with a wide range of professional or specialized skills have emerged, and they are more likely to be considered part of the team. Although they are not on staff, their presence and contribution is now viewed by many as a crucial component of quality care.

Institutional Care vs. Community Care

One major difference for volunteers working in institutional vs. those in community settings is the availability of staff and other formal support systems. In institutional settings, staff are generally available. In urgent situations, there will always be professional staff on duty. However in community care settings, the staffing level is not as high, and staff may not be present when the volunteer is working.

Volunteers should be educated in a variety of responses, including how to respond to situations when staff is not present. Staff support for these volunteers will take different forms, but it is essential to a successful volunteer program.

Case study: Heidi

Heidi volunteers in a telephone support service where she makes a weekly call to isolated seniors who are living at home. The organization's clients are predominantly Jewish. Heidi was born in Germany and moved to Canada with her family as a small child. She has a slight German accent and is concerned that this will upset some of her clients who are Holocaust Survivors.

Issues Raised in Case Study

- motivation of volunteers and staff
- education and Support from staff

Discussion

Heidi has a strong personal value in favour of community service and also a personal interest in the well-being of older adults. She chose to volunteer at this organization because of its reputation for excellent care of the elderly. After her initial orientation and training, Heidi became aware that a significant number of her clients were Holocaust Survivors. She expressed concern about the effect her accent might have on these people, and indicated she was willing to withdraw from any situation where her accent bothered a client.

Heidi showed awareness of possible triggers for negative memories in Holocaust Survivors. Her priority on client care was also commendable. The staff who worked with Heidi assured her that the clients' needs would come first. Then they spent some time talking to her about her own feelings as a German-born person, especially regarding the Holocaust and Jewish people. Heidi was feeling some guilt by association and found it useful to talk about these emotions. She also appreciated being given material to read about the reactions of other Germans and Jewish people. It was important to point out to Heidi that although her accent might be a trigger it also might not have any affect at all, since Holocaust Survivors are individuals and had individual reactions.

Case study: Rachel

Rachel is a Holocaust Survivor in her early 80's. She comes to the organization once a week to help out in a community program for seniors. She usually speaks with the same 10 to 12 clients every week and has developed a relationship with them. Generally she is a cheerful woman who is outgoing and able to make others smile. However, on days when she is reminded of her losses during the Holocaust, such as Yom Hashoah and other dates personal to her, she has difficulty performing her usual tasks. Rachel becomes weepy, and distracted. She then apologizes for her emotional outbursts and less efficient work.

Issues Raised in Case Study

- relevance of volunteer's own history
- priority of client care
- respect for the volunteer’s privacy
- opportunity for education, example
- opportunity for client/volunteer reciprocity

Discussion

Rachel is a valued volunteer, and staff make sure she knows that her work is appreciated, and also that having the occasional "off" day does not affect her overall performance. Staff asked Rachel how she wished to handle her assignments on those sensitive days. They also asked her how comfortable she might be sharing information about her own background with clients, staff and fellow volunteers. Rachel's primary concern was for her clients, and she said she would feel comfortable sharing her memories and feelings openly with all.

It was important evaluate the impact of Rachel's emotional distress on her clients. The professional staff interviewed her clients and determined whether interacting with Rachel when she was sad was having a negative impact. In fact, her clients appreciated the opportunity to give Rachel some comfort and support. Some Survivors who were Rachel's clients said they felt more comfortable being open with their emotions when she was with them.

The other volunteers who worked with Rachel had the opportunity to learn more about the effects of the Holocaust from Rachel's perspective. They struggled with their concerns for Rachel and their own tendencies toward "over protecting" her from her feelings. Rachel's openness provided a wonderful living example of overcoming adversity.

Case study: Norma

Norma is a widow in her mid-sixties. Each week, she visits with elderly residents in a local nursing home who are cognitively intact but physically frail. The volunteers in Norma's particular program were trained to make social visits to the residents and to notify staff if they noticed any changes. Urgent matters were to be reported directly to the nursing staff and any other changes to be reported to the Social Worker at the end of the volunteer's shift.

Norma commented in passing one day that one of her clients - Mr.G., a Survivor - had been suspicious of her again that week. He questioned who she was and her reasons for visiting him. She was able to convince him that her visits were purely social, and added that she was used to this type of paranoid behavior because "they are all like that".

Issues Raised in Case Study

Training must help volunteers determine what kind of observations should be reported to staff and when to seek staff assistance

Volunteers' personal histories and values affect their performance.

Volunteers' skills and abilities vary. Staff who assign volunteers must have a good understanding of the tasks how they "fit" with each volunteer's skills.

Discussion

Norma's husband was a Holocaust Survivor. He developed Alzheimer's disease and had died several years earlier. As his illness progressed, he had displayed some paranoid behaviour, which Norma had attributed it to his experiences during the Holocaust. Because she considered paranoia normal for Holocaust Survivor - "They are all like that" - she did not notify staff of the changes she observed in Mr. G .". After some discussion with Norma, it became apparent that she had not listened to all the education provided in the volunteer orientation. She felt she knew all about Holocaust Survivors, since she had been married to one for many years. Norma was very successful in her volunteer visiting role. The residents whom she visited obviously benefited from her company, and staff wanted her to continue. But they had to impress on Norma the need to respect the protocol and report any changes she observed. Although she may not have changed her feelings about the source of Mr. G's paranoia, Norma did agree to adhere to the policy.

Volunteer Appreciation

Organizations that benefit from volunteer efforts have a commitment to support those volunteers through providing education, offering assignments that have meaning, and expressing appreciation.

"You can never lose sight of the fact that this is work for which there is no monetary compensation. The rewards must be intrinsic because by the definition of "volunteerism" the rewards may not be extrinsic. It is your obligation, as the professional, to create those opportunities for intrinsic compensation. " (Duncan, 1995)

Appreciation is most valued when it is relevant to the work done and is appropriately delivered. Volunteers will not perceive appreciation events positively if they feel a lack of sincerity or respect. Each organization must design volunteer appreciation events that recognize the unique contributions of these men and women. Volunteers feel satisfaction when they observe that their work has a positive effect on clients. They often say that it is "my privilege" to help when the clients are Holocaust Survivors. Nonetheless, when appreciation is due, it should be given on behalf of clients and also on behalf of paid staff whose workload is lightened tremendously by the contributions of volunteers.

It is important that Survivors who can do so also have the opportunity to thank volunteers. Often these unique individuals are the only ones who can give justice to the expressions of appreciation given to volunteers. Including volunteers in community or institutional programs and events such as Holocaust Memorials, Holocaust Education Week etc. is another way to recognize their contributions. Where volunteers have specifically taken on duties devoted to Survivor issues, they should be identified within the Volunteer Department as individuals with unique expertise and commitment.

Student and Intern Placements in Agencies and Healthcare Facilities

Paula David, MSW, Coordinator, Holocaust Resource Project, Baycrest Centre Heather Lisner-Kerbel, MSW, Baycrest Centre

Whether they are nursing, medical, social work or other professional interns, the presence of students fulfilling practicum obligations in an agency or facility adds a new and enriching dimension for both permanent staff and clients. Their immersion in evolving academic knowledge, their mandate to acquire knowledge, and their enthusiasm can all contribute to enhanced care

Regardless of area, students generally have lower case loads than professional staff, and this gives them an opportunity to engage clients in a relationship that will be mutually rewarding. Holocaust Survivors, whether clients of community-based services or residents in long term care facilities, may take longer to develop attachments for and trust in care providers. Survivors often build a wall to protect themselves and understandably may be cautious with new people. However, Survivors -- like other older adults - may take great pleasure and interest in "their" young student, reaching out to help him or her in the learning process. The satisfaction of giving a student new insight about the Holocaust and sharing their own story can be therapeutic in itself. The student role can facilitate communication and client relationships when a sincere interest and willingness to learn is demonstrated.

Students come to a practicum or internship with a mandate to learn and grow. If their case load will involve Holocaust Survivors, it is imperative that students in all disciplines have some prior orientation to Survivor needs. An overview of the Holocaust - its impact on history, and in particular, its impact on a given group of older Survivors - will provide a range of benefits for all students. Students who have little prior knowledge of the Holocaust may be quite shocked or even disbelieving at the extent of the trauma inflicted on their Survivor clients. They require a general overview, and also an understanding of Survivors' diversity of experiences. Others may have had direct personal or professional experience, but again, these students may not be aware of the range of each individual's response to loss and trauma. In order to respond sensitively and effectively, students require preparation that includes a contextual understanding of the Holocaust and environmental triggers.

As discussed in other sections, caring for aging Survivors of trauma may be very disturbing for the caregiver. Student supervisors should understand the issues of counter transference and emotional burnout and be prepared to offer appropriate support. Working with survivors of trauma, torture and abuse is challenging and difficult for any professional. Students who have the opportunity to meet and work with elderly Holocaust Survivors, men and women who have lived over half a century "post-trauma," are in a unique position to listen to their narratives, to demonstrate caring and to offer support. Sometimes it is frustrating to recognize that we cannot right the injustices of the past and bring peace to a Survivor client. But it may help students to recognize how important their own contribution is in ensuring dignity and respect for Survivor clients. Supervisors should help their students recognize the unique potential of their efforts to support these special elderly clients.

Students should be encouraged to understand that the lessons learned in working with Holocaust Survivors have many applications. Once their placement ends, it's quite likely that most young professionals will never again meet a Holocaust Survivor. But they should understand the value of this experience in their professional development. Holocaust Survivors are the first survivors of genocide to live to their 80s and 90s in significant numbers. While it is a sad thought, knowledge gained in this work will preparation helping professionals to help the aging Survivors of genocides yet to come. The concept of environmental and psychological triggers must certainly apply to survivors of other extreme traumas.

The premise of this knowledge base is individualized care, founded on the elderly client's early life history and experience. Seeing beyond the initial presentation of "older adult" and caring about the journey taken to this point is sensitive practice in any helping profession. Understanding the nature of early life losses, the subsequent impact of post- trauma life changes and coping mechanisms, and viewing the client as a unique individual are all important lessons for any setting. Recognizing an individual's history and its subsequent effects on the aging process should be a critical part of best practice. Regardless of discipline, lessons that students learn from elderly Holocaust Survivor clients can later be applied to all elderly survivors of early life trauma due to war and extreme oppression.

Case Example: Social Work Student

Sophie, a warm and enthusiastic social work student was in her final year of the Masters Program and starting her practicum in a Jewish nursing home for the aged. Sophie presented with empathy and an eagerness to work with older adults. Growing up in a traditional Jewish family, she thought she was well versed in both Jewish religion and history. She was familiar with the Holocaust, since her grandparents were murdered in a concentration camp. However Sophie never really thought about concentration camps, or about what it meant to survive torture and trauma. Based on her lifelong interest in discovering more about her grandparents' story, she expressed an interest in working with Survivors.

Sophie's first client assignment was Mrs. R., an 87 year-old Survivor who had been in four different concentration camps and who was the only person in her family to survive the War. Mildly impaired, Mrs. R. still had vivid and accurate memories of her war-time incarceration. She herself recognized that her war memories were increasingly intruding on her daily existence in the form of flashbacks and anxiety. Sophie's supervisor, having ensured an introduction to the issues of Survivors in general, was prepared to support her in understanding this specific Survivor.

There were challenges from the initial meeting. When Sophie began discussing her difficulty engaging Mrs. R., supervisor and student talked about Mrs. R's reaction to Sophie. Sophie realized that Mrs. R. looked fearful each time they met. She didn't understand that Mrs. R. was terrified by the clicking sound of the young woman's high-heeled boots on the hard, hallway floors of the unit - a reminder of the boot-wearing Nazis who tormented Jews in the camps. Eventually, Sophie discovered that when she wasn't wearing her high-heeled boots, Mrs. R. appeared more relaxed. The "trigger" for the client's anxiety was finally identified, and Sophie dressed accordingly.

Tips

Prior to meeting patients and clients who are Survivors, students should have an overview of potential environmental and psychological triggers. Where possible they should meet a trained volunteer who is a Survivor and who participates in Holocaust education. Most cities have Holocaust Education Programs that offer speakers and resources, and these can provide valuable opportunities for learning.

Throughout the relationship between the client and the student, careful observation and consideration of unique needs is essential. Without comprehensive orientation and careful supervision, Sophie's responses to her client might easily have been more complex and less effective.

It is important not to categorize all Survivors; instead, we must "learn to listen" and "listen to learn." One student thanked the staff and the institution for the opportunity to open her heart to an incredible amount of learning and to confront her own fears of working with trauma victims. When working with elderly Survivors, this type of learning is constant.

Students from different religious, cultural and ethnic backgrounds should be given an overview of Jewish religion, culture and traditions. It will be reassuring for them to know that within the Survivor community, there is a diverse range of country-of -origin, language, religious practice and socio-economic background. Not only were Survivors' War-time experiences unique, so too were their pre- and post-War years. Experience has shown that, regardless of the fact that care providers come from another culture, older adults generally appreciate and will respond positively to a caregiver that is empathetic and interested.

The student's professional orientation will also impact on how she may be received by some Survivors. Medical and nursing students may face greater challenges, since they may be reminders of physicians and nurses who betrayed their ethics and values and destroyed lives in Nazi Europe. Mental health professionals may be viewed suspiciously for many reasons. Survivors (as previously explained) try not to appear vulnerable. Their early life experience has shown that vulnerability was often synonymous with death. After liberation, much of Germany's financial restitution program was based on Survivors "proof of harm. " Where there was no visible physical damage, Survivors were subjected to intrusive and insensitive mental status exams, including electroencephalograms (EEGs). This was traumatic for those who chose to endure these assessments. Those who refused did not receive compensation. Again, an advance awareness of potential difficulties and proactive responses may alleviate these challenges for both client and student.

As they should do with every client, students must be particularly aware of their professional relationships and the impact of 'saying goodbye to her clients when the placement is completed. Survivors may have issues of trust and question the commitment of a care provider. It is important to clarify the nature of the placement, the timeframe and prepare the client for the student's leaving, including reassurances that the client is not being abandoned.

Students must review which aspects of caring for aging Holocaust Survivors can be applied to or influence how they might best care for aging survivors of trauma due to war.

Caring for the Caregivers

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How to Deal with Stress and Potential Burnout

Providing Psychological Care

Listening to Holocaust-related narratives - and also silences about these events - can be at once challenging and rewarding for professional staff. Many Survivors respond well to caregivers who listen to their stores. This is a way for them to share their War-time experience and also to seek much-needed emotional support and empathy.

Listening with empathy and reacting appropriately can be difficult one who is giving professional care to an aging Survivor. Some clients and situations are so complex and upsetting that staff might wish to withdraw and not respond at all.

All staff who work Survivors should understand and recognize the impact of this phenomenon which is known as "counter transference." Witnessing the depth of pain, loss, fear and anger among Survivors and their adult children can be traumatic. It's not unusual for professional care providers to themselves feel helpless, angry, anxious, sad and even guilty. So long as these responses are recognized and appropriate supports are available, the burden should not become overwhelming.

The process of providing empathetic listening must be balanced with planned supportive team review and ongoing support, both from colleagues and ongoing professional development. All staff should have a colleague, supervisor or team member to provide opportunities for debriefing, support and collaboration. It is well documented that clinicians, in order to work effectively with victims of violence, torture and/or abuse, require ongoing professional development, smaller caseloads and collegial support. Holocaust Survivors belong in this category, and the professional staff must recognize the burden of their stories and the necessity for support in order to maintain clinical competence.

Providing Physical Care

Staff performing clinical examinations or procedures should know - in advance, if possible - whether a Survivor under their care experienced any abuse from "health care providers" during the War. Even if the person did not experience direct abuse, the threat was always present and real.

If attempts to provide medical or personal care are met with suspicion or resistance, staff should try to understand the source of such behaviour and avoid taking it personally. They should explain the nature of any procedure and also why it is being done. For example, if you are changing a dressing that might cause pain, let the person know what to expect. Discuss the need for this treatment and the anticipated outcome. Patients with some degree of cognitive impairment may need several reminders of this type during the course of each procedure. Be aware of the triggers that may present while you are with the patient - for example, your uniform, the need to ask personal questions, the need to remove the person's clothing an so on. A calm reassuring voice and language which helps the patient "remain in the present" can help ease the tension. Some patients may feel better if a family member or translator is present.

Families of Survivors: Emotional Impact

In many cases, adult children of Holocaust Survivors experience a transmission of their parents' early life trauma. The usual mixed feelings about changing care needs and the possibility that their parent will need to be placed in a long-term care facility is often exacerbated by the fact that they are children of Survivors. Any family would find it difficult to face a loved one's diagnosis of Alzheimer's Disease, but this may be particularly painful for Survivor families. Family members must be prepared to differentiate between long-standing traumas, recent traumas and how best to care for.

Reminders: Tips for Stress Relief

The Canadian Mental Health Association and the Heart and Stroke Foundation say the following strategies can help people deal with stress:

Deep breathing exercises, exhalation breathing, progressive relaxation exercise, stretching exercises, walking, meditation, social diversions and spiritual activities

Other Ideas

Hobbies: Whether you enjoy photography, crafts, sports or some other hobby - DO IT! Build time into your schedule to enjoy these activities on a regular basis. Consider it "nourishment for the soul."

Gardening: Whether you have a back yard or live in an apartment, consider the soothing quality of tending indoor and/or outdoor plants and watching them grow. The results of your work are obvious and you can enjoy watching your flowers, plants and vegetables grow day-to-day over many years.

Giving to others: Helping others takes attention away from yourself which can reduce anxieties and relieve stress. Find an organization whose goals you support and then volunteer to do something you enjoy. Donating money to charities is very worthwhile, but you may benefit more through personal involvement.

Vacations: Taking a break, for a weekend or a month, can be refreshing, but be careful. Vacations can be stressful if they are poorly planned, too expensive for your budget or if you are under constant pressure to make decisions about where to travel, eat and stay. Plan ahead and don't try to pack too much into the time available.

Enjoy nature: Go for a drive in the country. If you live in the city, make regular use of parks and nature trails. Smell the flowers, enjoy the trees and the birds - get away from the noise of the city whenever you can.

Training Suggestions

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The Holocaust and its effects on the post-War world in general, and on Jewish people in particular, have spawned a large and complex range of historic and social study. Although liberation occurred nearly 60 years ago, so long as there are living witnesses to the mass genocide, the final chapter cannot be written. In fact, it's quite possible that understanding of the depths of degradation and pain may be beyond our reach.

Survivors who are still alive today are nearly all in their 70s, 80s and 90s. They survived and an incomprehensible assault, but like all of us, they must face the uncertainties of age and poor health. Like all of us, they, too will one day pass away.

Clinicians who work with these elderly Survivors can easily be overwhelmed by the scale of the atrocities, and also by the resilience and strength these men and women showed in the post-War years. Even those with professional training in family violence issues or post-traumatic stress other than the Holocaust experience may not be prepared to work with this group of clients.

The importance of professional development in all disciplines cannot be underestimated. In order to meet the various needs of an agency or institution, trainers must have a flexible range of options. Such options must be relevant. They must effectively address the issues, yet be compatible with the needs and requirements within each discipline.

Here are two models for such training:

One Hour Training Session

This one-hour presentation utilizes material from this Manual. Customized Xeroxed handouts can make the session relevant to the trainee audience. Based on a traditional one hour in-service, the session provides an overview of the issues and directs attendees to follow-up articles specific to their own role. If the group is mixed, case examples from the participants can provide excellent material for discussion. Participants should be aware that this is an overview only, and should be left with a desire to learn more. Comprehensive handouts are critical, and sections from this Manual can be photocopied for this purpose. A possible structure for the session might be as follows:

- a Chronology of the Holocaust
- presentation of a 20-minute video relevant to the topic (recommended are Menorah Park's "Painful Memories", Baycrest Centre For Geriatric Care's, "CBC News, Baycrest Cares for Aging Holocaust Survivors" or a video relevant to your agency)
- a summary of "Environmental Factors and Potential Triggers" and "Communicating with Survivors - Terms and Translations"
- group discussion of personal experience and reactions to subject matter
- a selection of one to three articles chosen by the Trainer and maintained by the Coordinators given as part of the Training Manual Handout (Please refer to the Further Reading Section)
- standardized evaluations completed by both participants and trainer

A Model for Intensive Professional Development

In all professional disciplines, experienced clinicians should attend ongoing professional development sessions as a vital part of their practice. Often, in the course of daily practice, the occasional specialized workshop or lecture is offered. But such sessions do not usually recognize the range and richness of the participants' experiences and practical knowledge. The single lecture cannot ensure a sustaining confidence in change and the development of new approaches.

In highly specialized areas, the practicing clinician often proves to be more cognizant, flexible and responsive to changing clinical issues than the visiting "expert." It 's important to remember that the most relevant learning tends to happen on an informal basis, when practitioners feel comfortable and are willing to share questions, vulnerabilities and new approaches.

The challenge in forming this Professional Development Model is to capture and sustain both the spontaneity and sharing of the informal model, combining it with enough formality to define a common baseline of new information. The goal in developing an educational tool for practicing clinicians is to promote clinical expertise, collegial interaction and professional development in a way which is both cost- and time-effective.

Holocaust Education Group: A Pilot Project

Based on a pilot project with seven experienced clinicians from a range of services in a geriatric setting, the group model with a pre-defined structure has proven effective. Subsequent groups have expanded the concept and confirmed the success of the model. The resultant Holocaust Education Group combines the theory of the task-oriented group with the motivational benefits of the self-help group. In the task-oriented group, the product - in this case, increased clinical expertise - is the tangible and re-directing focus that allows members to enjoy the benefits of group participation. The self-help component empowers members to organize and sustain the Group based on mutual need and concerns. The leader becomes an external facilitator in both instances, ensuring that members proceed independently, taking full ownership of the Group's direction and the ultimate achievement of goals.

It is important to develop an atmosphere of mutual trust which is free of pressure, especially during the initial Group session. The topic is an emotional one, the time commitment is a large one for busy staff, and exposing vulnerabilities to one's peers can be threatening. However, the opportunity to learn in a supportive inclusive environment more than compensates for the difficulties. Articles and resources are distributed at each meeting for discussion at the next meeting, but there is no pressure to comply, and the Group might decide to use the articles only as shared ground for examining different issues. When the expectations and standards are defined by the participants, the resultant effort is often more ambitious.

Both individual members' perspectives and the mutuality of the Group process allows for unique learning. Participants in these study groups have unanimously defined the experience as positive, citing new knowledge, heightened sensitivity and increased mutual respect for colleagues as the most positive outcomes. Obviously, regardless of professional commonalties, the individuals within each Group define the direction, tone and outcome of the series. Therefore, each Group series examines the issues from different perspectives, using different case studies, and contributes unique insights, approaches and conclusions. The potential for professional growth in this context is open-ended and dynamic.

The Development of a Peer Study Group on Caring for Aging Survivors

Convene a small group for mutual support and professional development. Five to seven members are an optimum number for both diversity and group intimacy.

The facilitator should develop guidelines, learning goals and documentation format prior to the first group meeting to allow members scope for discussion and further development.

Establish a theoretical theme of mutual interest to all group members.

Six sessions of one-and-a-half hours each (timing and frequency of sessions to be determined by group members at the first meeting) allows for group formation, academic development and practice-related analysis.

In order to develop the pilot group, a facilitator was assigned, as was the topic. This is recommended for initial group series, after which continuation would be based on group discussion, commitment and joint participation in preparation, subject matter and evaluation.

Recommended Group Meeting Outline

Session One:

This meeting should deal with both "housekeeping" concerns and clarify individual and group goals. A definition of practice area and methods of operationalizing the sharing of knowledge and new material is established. Members divide responsibilities such as room bookings, photocopying and accessing articles for the duration of the series.

Session Two:

This is the opportunity to develop a group definition of the subject matter and to explore personal and professional experience within the topic area. A relevant article that has been read prior to attendance is useful as a basis for discussion.

Session Three:

This session bases a "round-table" discussion of individuals' personal life perspective on the topic area, encouraging biases, questions and the use of self in light of the particular subject matter. Individualizing members' experience both academically and experientially highlights how personal styles and individual differences further enrich the learning in the safety of a group experience.

Session Four:

Individual members who feel comfortable resenting an article, which should be pre-distributed and pre-read by members, should be prepared to lead the discussion. By this time, the group format encourages lively debate, personal perspectives on the topic at hand and a continued discussion of actual case examples.

Session Five:

At this stage, the group should be assessing the topic area for its role in a geriatric setting and how to make practical use of discussion material within individual services. Consideration should be given to evaluating the learning process, the results obtained and concrete methods for translating new learning to everyday practice.

Session Six:

This is a session for evaluation and closure. Each participant should complete a brief, written evaluation. This ensures an assessment of the group learning approach, the expansion (if this has occurred) of a knowledge base, and predicted effects on current practice. A group member must take responsibility for preparing and collating the evaluations. Part of closure should allow group members to decide whether to begin another group series on another topic and what steps are necessary for that process. Copies of articles discussed should be attached to the final evaluation.

Further Resources

Links

Sandi Pelly, B.A.

www.Nizkor.org
"Nizkor" is a Hebrew word; it means "We will remember." This site is, and always will be, under construction. It contains articles and information written to provide the truth about the Holocaust. The home page states that "The real purpose of Holocaust revisionism is to make National Socialism an acceptable political alternative again."

www.Remember.org
This web site shares art, discussion, photos, poems, and facts to preserve powerful Holocaust memories.

www.USHMM.org
The United States Holocaust Memorial Museum is America's national institution for the documentation, study, and interpretation of Holocaust history. It also serves as America's memorial to the millions of people murdered during the Holocaust.

Chartered by a unanimous Act of Congress in 1980 and located adjacent to the National Mall in Washington, D.C., the Museum strives to broaden public understanding of the history of the Holocaust through multifaceted programs including exhibitions; research and publication; the collection and preservation of material evidence, art, and artifacts relating to the Holocaust; annual Holocaust commemorations known as the Days of Remembrance; distribution of educational materials and teacher resources; and a variety of public programming designed to enhance understanding of the Holocaust and related issues, including those of contemporary significance.

www.claimscon.org
The Conference on Jewish Material Claims Against Germany works to secure compensation and restitution for Survivors of the Holocaust and the heirs of Holocaust victims.

Since 1951, the Claims Conference - working in partnership with the State of Israel - has negotiated for and distributed payments from the governments of Germany, Austria and other countries, and also from certain industry groups. It has also recovered unclaimed German Jewish property and funded programs to assist the neediest Jewish victims of Nazism. So far:

More than 500,000 Holocaust Survivors in 67 countries have received compensation payments as a result of the work of the Claims Conference.

Payments to Holocaust Survivors as a result of Claims Conference activity amount to more than $50 billion to date.

The Claims Conference has allocated more than $600 million to organizations which are involved in meeting the social service needs of Holocaust Survivors and/or engage in education, research, and documentation relating to the Shoah (Holocaust).

www.amcha.org
There are many organizations and institutions that memorialize those who died in the Holocaust. AMCHA cares for the survivors who are still alive.

AMCHA was founded in 1987 by a small group of Dutch survivors headed by the late Manfred Klafter who served as AMCHA's President until his death in February, 1997. From its beginnings in a small apartment in Jerusalem's Bayit Vegan neighborhood, AMCHA has grown to encompass four large branches in Israel's major cities and smaller satellite locations across Israel.

AMCHA reaches out to:

those who experienced the horrors of the Shoah as adults

child Survivors who were robbed of their youth, and

children of Survivors, the Second Generation, who were profoundly affected throughout their lives by events they can only imagine.

Further Reading

Paula David, MSW, Coordinator, Holocaust Resource Project, Baycrest Centre

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Feedback and Other Forms

We are constantly learning about caring for Holocaust Survivors as their needs change with age. Providing care to this group has always been a learning process and we are continuously discovering new triggers, new strategies and new information about caring for this diverse group.

Recognizing that this is an ongoing, evolving process, we welcome your contributions. If you would like to share knowledge and experiences which would add to the information in this manual, please contact Anne Max at 416-785-2500, ext. 2259.

Support Groups

E-Journal: If Not Now

"If Not Now" is an Internet Journal" dedicated to providing optimum care and understanding for aging survivors and their families. We are interested in opening communications with professionals and agencies working with survivors involved in health care, community agencies, social and recreational services, restitution and reparation. We want to hear from survivors and their families, opening an ongoing dialogue across the international community. Your comments and discussion are welcome, as well as suggestions and submissions for future editions.

Holocaust Related Support

- Second Generation Support Group
- Child Survivor and Hidden Children's Group
- Baycrest's' Apotex Survivors Support Group
- Baycrest's' Terraces Survivors Group

Café Europa

Café Europa is a free, gathering place for people who have survived concentration camps, labour camps, exile, were in hiding or members of resistance and partisan groups. Café Europa offers a social morning together, is a chance to visit with old friends, meet new ones, hear stimulating lectures, join in lively discussion and listen to music and have a good time.

Refreshments are provided. Baycrest is a kosher facility and no outside food is permitted. To learn more about The Café please visit Baycrest.org.

Order the Book

If you would like a hard copy of the Manual, *Caring for Aging Holocaust Survivors: A Practice Manual*, please contact Anne Max at 416-785-2500, ext. 2259 for further information.

Baycrest Centre
for Geriatric Care

Caring for Aging Holocaust Survivors
A Practice Manual

Editors

Contact Us

Counselling and Referral for Seniors and Caregivers

This service is made up of experienced, knowledgeable social workers who respond to your inquiries. Our staff is here to counsel; educate and help seniors, their families and caregivers understand their options and make informed decisions, particularly during periods of transition or change. We provide information about community resources and assist individuals to access the Baycrest and/or community services they require.

These free services include:
Navigating the 'system', problem solving, individual and family counselling, caregiver counselling, caregiver education, consultation for future planning, connecting individuals to the appropriate resource at Baycrest and other agencies and services and transition assistance to new residents of the Jewish Home for the Aged (Apotex).

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Web: www.baycrest.org

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