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Beyond the Bima - Jews Facing Chronic Illness:
What is the role of a Jewish Palliative Care Chaplain?

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Acknowledgements

One of the first things I heard upon coming to the HUC-Cincinnati campus my second year is that relationships are one of the most important things we have supporting us in life and that every encounter has the potential to become something more. This is true.

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PRECIS

The purpose of this thesis is to provide an examination of Jewish healthcare chaplaincy in the United States and its ability to meet the palliative care needs of the future Jewish community. I will present a study of the history and development of the Jewish viewpoint on the spiritual aspects of palliative care, as supported by Jewish texts. At this time, Jewish healthcare chaplaincy struggles to address the needs of Jewish patients, synagogue affiliated and otherwise, who are facing chronic and life-limiting illness. The nation's population, as a whole, is aging and by 2034, there will be more older adults than children.[1] The trajectory of the Jewish community is no different. This thesis will suggest ways in which Jewish chaplaincy can adapt to serve their Jewish constituency.

In the first chapter, this thesis provides an outline of the issues confronting chaplaincy today, when serving Jewish patients who face chronic and life-limiting illness. I will consider the overarching questions about this type of pastoral care and these issues will be addressed throughout the remainder of this thesis.

In chapter two, I will present a thorough glossary of terms and definitions necessary for understanding the different issues to be discussed. Because of the growth of American medical care specialties there is often a confusion of terms. This chapter will provide a common dictionary from which clearer communication can be achieved.

Chapter three is a survey of Jewish texts from which chaplains can provide guidance to Jewish individuals who must make medical decisions regarding the treatment of their chronic or terminal illnesses. Texts from the Bible and Talmud will be examined, along with current interpretations and advice pertinent to contemporary times.

The fourth chapter discusses medical care for the chronic and terminally ill. The general history of palliative and hospice will be traced, as they emerged as distinct disciplines.

Chapter five will review how chaplaincy has evolved into a profession that now includes pastoral care providers on the interdisciplinary team treating people with chronic

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[1] https://www.census.gov/library/stories/2018/03/graying-america.html

and life-limiting illnesses. This chapter will outline the way that chaplaincy developed from a Christian foundation into a field that has become more inclusive of other faiths and approaches to life and death. Included in this chapter will be the voices of Jewish chaplains interviewed about their experiences and views on providing spiritual support to Jews.

In the concluding chapter of this thesis. I will review a number of recommendations, my own, and others' proposed solutions for Jewish chaplaincy in the future. My own thoughts and what I have learned in this process will be included.

Methodology

The following chapters are based on my studies of both historic and contemporary Jewish texts and responsa that address the Jewish medical and pastoral approach to caring for others. I conducted interviews with Jewish chaplains and rabbis serving in hospitals and care facilities as well as hospice, physicians, and nurse practitioners. I had numerous conversations with medical personnel in hospitals and hospice facilities. Each individual formally interviewed was asked about their experience as a chaplain or with a chaplain; the changes they have seen during their tenured medical careers or treatment; their thoughts and experiences with palliative care, and the future of the role of palliative care teams.

When I completed the interviews, I organized the resulting data based on their recommendations, then included their positive and negative conclusions along with my own recommendations.

I would like to thank the individuals below for the time and guidance they gave to the research process:

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PREFACE

Birth, and death are the only two common experiences shared by humanity. When babies are born, the dream is that for first few months or years of life, their experience is that of being coddled. They are cared for and pampered by loving adults, and they are never truly alone, as they transition from infant to toddler and onward. There is a plethora of advice for new parents and caretakers on how to do this.

Sadly, I cannot write the same for the inevitable outcome of the miracle of birth, when, hopefully after a long life, we experience decline, loss, and death. In the United States, the final stage of life and our transition beyond this world is rarely the rosy-colored dream of a quiet, good death, in bed, at home with family nearby. Seventy-one percent of Americans say that they want to die at home, yet only twenty-five percent of them do. Instead, old age, and chronic illnesses are accompanied by loss of loved ones, physical abilities, and loss of familiar surroundings. American older adults are often alone, at home, in group living facilities, or in medical settings. They are bereft of companionship and their faith communities on their final journey on earth. I view this as being at odds with Jewish spiritual values. There is a need to provide ongoing spiritual accompaniment to older adults and those with chronic illness.

The United States is experiencing an “elder boom.” People are living longer than ever before, and the baby boomers born between 1946 and 1964 are currently aging into the final quarter of their lives. Simultaneously, due to advances of healthcare, people are also often sicker longer, with chronic illnesses. Without spiritual support and guidance to guide a deeper examination of one’s values in dealing with chronic illness and end of life care choices, how does one prepare for the last years and make reasonable decisions, weighing healthcare choices and life goals/experiences? Can improved Jewish chaplaincy support Jews on their individual journeys, walking with them on their path of chronic, or terminal illness? How can this be done, in the face of increasing numbers of individuals with chronic illness?

This thesis will examine the history and current ways chaplaincy, and specifically, Jewish chaplaincy, can support individuals experiencing chronic, or terminal illness. My goal with this paper is to examine and assist the role of a Jewish chaplain, in order to achieve the goal of spiritual care and accompaniment as individuals make their own life choices.

CHAPTER 1: THE PROBLEM BEFORE US

> *"A test of a people is how it behaves toward the old. It is easy to love children. Even tyrants and dictators make a point of being fond of children. But the affection and care for the old, the incurable, the helpless are the true gold mines of a culture."* – Abraham Joshua Heschel[2]

How will our society measure up to the Heschel test?

American Jewish society is confronting numerous problems. People are living longer than ever before, and the population as a whole is aging.[3] Synagogue and traditional Jewish connections are fraying and downsizing, providing less support to their constituencies. Unaffiliated Jews are increasingly alone as they confront aging, illness, and loss. This thesis will examine the current state of spiritual support and the healthcare industry, examining the history and development of the Jewish viewpoint on the spiritual aspects of palliative care, as supported by Jewish texts. My goal is to answer the question of how Jewish chaplains can support Jews dealing with chronic and life-limiting illness.

Let us start by examining the American demographic. The US population is aging – and by 2034, there will be more older adults than children.[4] According to the US Census, "In 2014, Americans ages 65 and older were 15 percent of the total U.S. population; by 2060, that share is projected to grow to 24 percent.[5] American society is experiencing more people living and, living longer. Jewish Americans are slightly older than the US population. Among

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[2] Rabbi Abraham Joshua Heschel, "To Grow in Wisdom," *The Insecurity of Freedom: Essays on Human Existence* (New York, 1955)
[3] R. Sean Morrison M.D, Mireille Jacobson "Palliative Care Works, So Why Is It Rarely Used? Follow the Money." STAT (2021). https://www.statnews.com/2021/03/23/palliative-care-works-so-why-is-it-rarely-used-follow-the-money/.
[4] https://www.census.gov/library/stories/2018/03/graying-america.html
[5] U.S. Census Bureau, Projections of the Size and Composition of the U.S. Population: 2014 to 2060, March 2015. http://www.census.gov/content/dam/Census/library/publications/2015/demo/p25-1143.pdf

adults, the median age in the Jewish population is 49 – slightly older than the median age of adults in the general public, which is 46. To view this another way, roughly half the adults who identify as Jews are over age 50, compared to the 45% of non-Jews in the US. There are more older Jews, by percentage of population.[6]

Medical advances are also keeping people alive longer, but that longevity is often accompanied by chronic illnesses. “We do not appear to be moving to a world where we die without experiencing disease, functioning loss, and disability,” says Eileen M. Crimmins, a professor of gerontology at the University of Southern California (USC).[7] When chronic illness is a part of the process of physical decline, how is the patient supported, spiritually as well as physically? How can they be guided to examine their beliefs and values in order to have truly informed decision-making, when setting goals of care. We will look at how medical care has adapted in the past. Could earlier medical transformations inform contemporary choices? The goal is to support the Jewish chaplain by giving them additional tools to help the patient in clarifying their values and priorities as they face chronic illness and aging.

From the demographic problem ahead of us, let us look at the situation of spiritual and religious affiliation. With the decline in synagogue membership and general Jewish education, many Jews are set adrift from Jewish teachings, and the ways that Jewish texts can inform choices today. We may know that Judaism emphasizes that human life is precious and must never be extinguished prematurely, but when it comes to chronic illness and aging, the details of how to hold that precious life in balance with pain and loss can be less clear. There

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[6] https://Pewresearch.org/religion

[7] Freeman, Kris S. "Aging: U.S. Lives: Longer but Sicker?" *Environmental Health Perspectives* 211, no. March (2011).

is no obvious support mechanism taking the place of 'go ask the rabbi.' Americans are increasingly labelling themselves as "Spiritual but not religious" (SBNR)[8]. So, to whom do those individuals turn for spiritual comfort and guidance, when a patient and family are confronted with the diagnosis of a chronic, life-limiting and/or terminal illness? Without support in examining one's core values and hopes in life, upon what does an individual base decisions around medical treatments which may also have consequences for the patient's goals in life.

As chronic illnesses and fatal illnesses approach their natural outcomes and the end of life nears, how does one address the mental and spiritual needs of the individual who is afflicted? What religious guidance could be shared to help a Jewish patient review their goals of care and symptom management? Should one have to die in a bustling hospital, attached to machines keeping their body alive, as so many do? We are challenged by the statistic cited earlier from the 2017 Keiser Family Foundation finding that 71% of individuals say they would prefer to die at home, but only 24% achieve that.[9] Could healthcare and spiritual care evolve and together support patients in accomplishing this goal, by managing pain and other symptoms as well as having existential conversations?

Chaplaincy can provide the opportunity for conversations regarding faith, values and hopes, alongside treatment options, in support of the patient's desires. The chaplain, an individual serving as a spiritual guide, can help the patient and their family clarify their values/faith and priorities, and move the patient's conversation forward. Chaplains, however, are often not included in such goals of care discussions and only called in toward the end of a

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[8] https://www.pewresearch.org/fact-tank/2017/09/06/more-americans-now-say-theyre-spiritual-but-not-religious/#:~:text=About%20a%20quarter%20of%20U.S.,June%204%20of%20this%20year.

[9] https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings/

patient’s illness. This is a serious problem, when data suggests that patients with chronic and life-limiting illnesses have spiritual concerns, and would like to have spirituality addressed. Unfortunately, less than 50% of physicians believe that it is their role, nor are they equipped to address those concerns.[10] The New England Journal of Medicine report goes on to say,

> “An observational study by Winkelman et al. showed that patients with cancer who had unmet spiritual concerns were more likely to have significantly worse psychological quality of life than those whose spiritual concerns were addressed. In addition, a multisite cohort study involving 343 patients with advanced cancer showed that the patients whose spiritual needs were supported received more hospice care and were less likely to have burdensome nonbeneficial interventions near the end of life than those whose needs were not met and, furthermore, that spiritual support from the medical team or chaplain was associated with higher quality-of-life scores.[11]

This article documents that the need for spiritual support has never been absent from individuals with chronic or life-limiting illnesses. In the American medical culture, it is often going unmet.

The goal of this thesis is to examine how to have a patient and their family benefit from a more integrated lens in gaining information and making decisions regarding their treatment options. I will establish a common terminology, describe Jewish values for the guidance of and care of chronically ill individuals, as well as what palliative care and hospice can provide for a patient. I will address the support Jewish chaplains have provided, historically and currently. This paper will close with where I believe the field of Jewish palliative care chaplaincy should develop, in order to provide support to Jews throughout the wide expanse of the American Jewish community.

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[10] Amy S. Kelley, M.D., M.S.H.S., and R. Sean Morrison, M.D. "Palliative Care for the Seriously Ill." New England Journal of Medicine 373 (2015).

[11] Amy S. Kelley, M.D., M.S.H.S., and R. Sean Morrison, M.D. "Palliative Care for the Seriously Ill." New England Journal of Medicine 373 (2015).

CHAPTER 2: TERMINOLOGY

Every specialty field and career develops its own jargon and shorthand for communication. When an individual changes careers, they are often confronted with words that have new meanings and sentences whose meanings are obscure until the individual learns this new terminology.

It is a similar experience when we become sick enough to require professional medical care. As patients, we enter a world that may feel as if the inhabitants are speaking a foreign language. As the patient and their family engage with the medical community , there is a great potential for miscommunication or misunderstandings due to different understandings of the terms used. This paper uses terminology that may cause some unintentional discomfort to the reader. Therefore, I am providing definitions of the terms that I'll be utilizing. Words as labels have varied meaning and shadings to each individual. My intention is to provide a close definition to avoid such misunderstandings. For the purposes of this thesis, I will also provide an explanation for the reason that I have chosen to use the specific words and terminology. While I may have my own groupings for these terms, this lexicon of terminology is arranged alphabetically.

Chaplain: The term "Chaplain" is derived from Medieval Latin, *cappelanus,* meaning clergyman of the cloak. Tradition states that St Martin of Tours cut his cloak in half to share with a beggar. The other half of the cloak became a Roman Catholic relic, guarded by the *chapelain.* The term was extended to Christian clergy who served outside of a church.[12] So, it

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[12] www.etymology.com

should be understood that a chaplain is an individual who provides spiritual care for individuals outside of a religious institution. Chaplains today are no longer by default Christian. However, many patients assume a chaplain is Christian.

For the purposes of this paper, the term "chaplain" denotes an individual who is often an ordained clergy member of a recognized faith tradition and has been endorsed though that faith tradition's authoritative body and accredited by one of three national chaplaincy organizations; the Association of Professional Chaplains (APC), which certifies chaplains from all faith traditions, Neshama: the Association of Jewish Chaplains (NAJC), which only certifies chaplains from the Jewish tradition, or the National Association of Catholic Chaplains (NACC), which only certifies chaplains from the Roman Catholic tradition.

The chaplain's role is to offer spiritual guidance and pastoral care to patients, their families and the medical teams and in accordance with the patient's spiritual context. A chaplain does not proselytize for any particular faith tradition. A chaplain need not share the same faith tradition as the patient. Chaplains support and work with people of all religious faiths and are familiar with beliefs across many different cultures. Chaplains serve in different areas of society, including, but not limited to the Veteran's Administration, the military, healthcare, schools, correctional institutions, and corporate venues.

This paper will focus primarily on the role of a chaplain serving in the healthcare field. They work with the patient, and staff, to provide spiritual care in a non-religious organization. Chaplains engage with the patient and patient's family to assist them in understanding, qualifying and articulating their values and priorities for their life. Those choices, in turn, can be expected to guide medical care choices. Chaplains customize their approach based on an individual's background, age, or medical condition.

Chronic Illness: Broadly defined as an illness or condition that lasts 1 (one) year or more and will require ongoing medical attention, and potentially limit activities of daily living of the patient, or both. Diseases such as heart disease, cancers, and diabetes are considered chronic and life-limiting. They are the leading causes of death and disability in the United States and are leading drivers of the nation's $4.1 trillion in annual health care costs.[13]

I have chosen to use this term as it is foundational to palliative care. Individuals with chronic illnesses will be engaging with the medical industry longer than most patients, and are at risk of receiving treatments which result in other symptoms and side effects and potentially induce other illnesses.

Elderly/Aged/Older/Seniors: Anyone can experience a chronic illness and receive palliative care. This paper will address patients of all ages. I will use the term "older adults" when referring to patients over 70. Aging, an inevitable process, is commonly measured by chronological age. However, the aging process is understood now to be more of a "spectrum," of aging. There is no uniform progression of aging across the population due to differences in genetics, lifestyle, and overall health.[14]

Euthanasia: Since the end of the nineteenth century, the term euthanasia has been used to denote the deliberate ending a person's life by medical means, to relieve suffering.[15] This word is derived from the Greek; "Eu" or good, and "Thanatos" or death, or, "good death." That current meaning of the word has evolved from its original usage, before the end of the nineteenth century. Before the late 1800's, euthanasia denoted a peaceful, natural death,

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[13] https://www.cdc.gov/chronicdisease/about/index.htm

[14] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4282767/#:~:text=Ageing%2C%20an%20inevitable%20process%2C%20is,referred%20to%20as%20'elderly'.

[15] Clark, David. To Comfort Always: A History of Palliative Medicine since the Nineteenth Century. Oxford: OUP Oxford; Illustrated edition, 2016. P.1

ideally at home, surrounded by family. It was in no way physician or family-assisted suicide. Physicians who studied euthanasia in the classical sense outlined the goal of a comfortable death. The physician attending was to take the utmost care not to hasten death in any way, as palliation for pain or other symptoms was administered.[16]

I will be using this term when discussing the history of hospice and in contemporary stereotypes. I will clarify when using the term as to which context I am referring.

<u>Home Health Care:</u> There has been an expansion of health care received by a patient in their home in the past decade, and for good reason;

> "Home health care is a wide range of health care services that can be given in your home for an illness or injury. Home health care is usually less expensive, more convenient, and just as effective as care you get in a hospital or skilled nursing facility (SNF)."[17]

Home Health Care requires a doctor's orders to commence, with a home health agency resource working with the patient and communicating about progress with the doctor.

<u>Hospice Care:</u> The word *hospice* comes from the Latin *hospitum*, meaning "guest house, hospitality." *Hospice* traditionally meant lodging for travelers, often run by a religious order like a church or monastery.[18] Hospice care is the term for individuals travelling towards the end of their life. Hospice care begins when the patient is no longer pursuing a cure for their illness. This can occur at any time. In the US, however, related expenses of hospice care are covered by Medicare, when the patient has a life expectancy of less than six months.

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[16] Munk, William. *Euthanasia: Or, Medical Treatment in Aid of an Easy Death.* London: Longmans, Green and Co, 1887.
[17] https://www.medicare.gov/what-medicare-covers/whats-home-health-care
[18] https://www.vocabulary.com/dictionary/hospice

Hospice care in this country is provided by a multidisciplinary team focused on providing physical, emotional, and spiritual care for the patient, and their family, at the end of life. The patient receives treatment for their symptoms and pain. Hospice care can be provided at the patient's home, or in a facility such as a skilled nursing facility, hospital, or even in a separate hospice center.[19] A crucial difference between palliative and hospice care is that hospice care became a Medicare reimbursable benefit in 1982.

I am including hospice care in this document because it is so often conflated with palliative care. The two terms do not refer to the same subject. Hospice care is a subset of palliative care. A patient with a prognosis of six months left to live could go into hospice care. The patient would receive palliative care, to address symptoms such as pain, nausea and anxiety, as their disease progresses to end of life. All hospice care IS palliative care, however, not all palliative care is hospice care. In contrast to the patient going into hospice, a patient could still be pursuing therapeutic treatment, working towards a cure, could simultaneously receive palliative care for related symptoms. Palliative care is symptom management and can be ongoing throughout a patient's illness.

Long Term Care Facility (LCTF): The National Institute on Aging defines a LCTF as involving "a variety of services designed to meet a person's health or personal care needs..."[20] These services help people live as independently and safely as possible when they can no longer perform daily activities on their own and are unlikely to regain the capacity to do so. These activities include bathing, toileting, grooming and transferring (getting out of bed, shifting from a wheelchair to the toilet, entering/exiting a vehicle) People often need long-

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[19] https://www.hswo.org/hospice-care

[20] https://www.nia.nih.gov/health/what-long-term-care

term care when they have a serious, ongoing health condition or disability. The need for long-term care can arise suddenly, such as after a heart attack or stroke. Most often, however, it develops gradually, as people get older and frailer or as an illness or disability gets worse.[21] Long term care can be provided by paid professionals or unpaid friends and family members. Older labels for LCTF include "retirement home" or "nursing home."

There are several types of care, and care facilities, beyond hospitals, which provide care for individuals with chronic illness. I will describe and differentiate them in this section. The reader will want to keep in mind, however, that the different types of care may be given in the same facility. It is important to understand the differences between them, as the illness progresses.

Palliative Care: The word, palliative, comes from the French word, *palliatif*, which in turn came from the Middle Latin *palliates*. *Palliative* was first recorded as an adjective in the 1540's, and then later as a noun in 1724. The Latin root is pallium, or cloak. To *palliate* is to "cloak the symptoms", or alleviate without curing.[22] Palliative care focuses on alleviating symptoms, such as pain, discomfort, and stress of a patient. It is appropriate at any age and any stage of a serious illness, not just end-of-life.

At its core, palliative care is a person- and family-centered approach to care, involving an "interdisciplinary pursuit of the quality of life in the context of serious illness."[23] Examples of these illnesses are cancers, diabetes, dementia and heart failure. Palliative care can be provided along with curative treatment and may begin at the time of

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[21] https://www.nia.nih.gov/health/what-long-term-care
[22] https://www.vocabulary.com/dictionary/palliative
[23] https://www.youtube.com/watch?v=HBGtLZHKgZI B.J. Miller

diagnosis.[24] The patient's goals and priorities provide the core aim of the care plan. Palliative care does not replace the patient's primary therapeutic treatment, but works in conjunction with it. A patient can receive palliative care for their symptoms, such as nausea or pain, as they pursue a cure for their chronic illness. The palliative care team, patient, and the family of the patient work in conjunction with the therapeutic team. The patient and palliative care team define and clarify the patient's values, and goals for their life. In general, palliative care is focused on helping patients and families understand their choices for medical treatment and likely impact and outcomes of treatment. It can be performed on an ongoing, outpatient basis with an agreed-upon goal of avoiding emergencies and hospital stays.[25] Currently palliative care as a whole is not a directly covered by most insurance companies and Medicare. While some aspects of palliative care are covered, it is a patchwork.

I am defining this term as beyond symptom/pain management by medical staff, to include ongoing conversations with a spiritual care and social care resources, to understand how the patient sees the progression of their illness, and prioritize their life goals and activities.

Patient-Centered Care: "Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions."[26] Achieving patient-centered care means to work with the patient, using their language, to learn their values and goals for their life. It means understanding their goals and

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[24] https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care

[25] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9230914/

[26] Institute of Medicine. "Crossing the Quality Chasm: A New Health System for the 21st Century"

communicating as clearly as possible, in simple terms, the risks and benefits of any treatments.

I have chosen to use this term because it encompasses the stated goal of most care facilities and caregivers. However, I believe that most facilities fall short of patient-centered care, instead delivering treatments and therapy without consistently communicating likely outcomes of treatments and checking in with patient regarding their values and life goals.

Religion: A personal set or institutionalized system of religious attitudes, beliefs, and practices. This can include the service and worship of a God or the supernatural, and a commitment, or devotion to faith or observances.[27] This may include texts, practices and beliefs which fosters a sense of connectedness and meaning.

This paper will not use spirituality and religion interchangeably. For the purposes of this paper, spirituality is the broader set of beliefs and practices which are often left unspoken.

Skilled Nursing Facility (SNF): This is another form of a non-hospital-based medical service which provides care for individuals with chronic illness. A SNF can also be labelled, "in-patient rehab" for a patient to receive skilled nursing as they recover from a medical event, and before they return to their home, or other living situation. Medicare defines skilled care as "nursing and therapy care that can only be safely and effectively performed by, or under the supervision of, professionals or technical personnel. It's health care given when the patient needs skilled nursing or skilled therapy to treat, manage, and observe their condition, and evaluate your care."[28] These facilities can have overlap with an LTC, however the SNF

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[27] https://www.merriam-webster.com/dictionary/religion

[28] https://www.medicare.gov/coverage/skilled-nursing-facility-snf-care

can also provide short-term stays for patients in rehabilitation with full expectations of returning to independent living.

Spirituality: Having to do with deep personal approach to meaning in life. There are often religious, feelings and beliefs, including a person's sense of peace, purpose, connection to others, and beliefs about the meaning of life.[29] Spirituality can be a response to questions like, "Why am I here?" Spirituality reflects a person's sense of connectedness, to themselves and others. Some people often state that they are "spiritual, not religious" to indicate that they have beliefs, but may not belong to any organized religious institution.

Telehealth: This is a healthcare delivery mechanism delivering health care services, outside of physical buildings. Patients and providers are separated by distance. They are connected by information and communication technology (ICT).[30]

Therapeutic care: Therapeutic care is also termed "curative care." It is care given with the goal of curing an illness or condition. An example of therapeutic care is a cast for a broken bone, and surgery or chemotherapy for cancer. The term(s) are also used for treatments which simply delay disease progression even when a cure is not possible.

I have chosen this term to qualify and differentiate the types of treatments available to individuals, as well as to note that many cancers are not curable, but their progress can be slowed.

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[29] https://www.cancer.gov/publications/dictionaries/cancer-terms/def/spirituality

[30] Fabian Winiger (2022): The changing face of spiritual care: current developments in telechaplaincy. Journal of Health Care Chaplaincy

CHAPTER 3: JEWISH VALUES AND GUIDANCE FOR CARE OF THE CHRONICALLY ILL.

This chapter will review foundational Jewish texts and halakhah from Torah, Talmud and rabbis regarding treatment of the sick. The purpose of this is to provide historical, textual guidance to Jewish patients and chaplains as they consider their treatment options. We will examine traditional texts and halakhah regarding medicine, healing and visiting the sick and read how they have been applied through time to guide Jewish choices regarding spiritual and medical treatment of the ill.

Foundational Texts

Judaism values life above all. This is a core tenet of Jewish faith. The concept of preservation of life is termed "פקוח נפש," and is derived from Leviticus 18:5 which states, "You shall keep My laws and My rules, by the pursuit of which man shall live: I am Adonai." Rabbinic Judaism derives the concept of *pikuach nefesh* the command to save a life or soul, from that text. They emphasized the "man shall live in pursuit of the laws" concept, which later grew into the corollary that we are to "live by the commandments, not die by them."[31] *Pikuach nefesh* takes precedence over every other commandment except for murder, idolatry and incestuous sex.[32] Even Sabbath-observant Jews are obligated to violate Shabbat's work restrictions, in order to save a life. This precept comes into play with chronic

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[31] Babylonian Talmud, Yoma, 85B

[32] Bablonian Talmud Sanhedrin 74A

illnesses, their progression and the decisions made by the patient and medical teams. The patient is obligated to accept treatment to preserve their life.

In the oldest surviving Jewish texts, one can read barely a trace of the concept of chronic illness. Much more consideration was given to choices and behaviors at the end of life. When the Talmud does not explicitly deal with a topic, other methods developed to assist rabbinic Jews in halakhic decision-making. There is a reasoning process to make analogies to arrive at decisions, especially around chronic illness. However, the overarching commandment will always be to act in order to save a life. We will re-visit this concept in the framework of chronic and life-limiting illness.

When a person falls sick, it is considered a mitzvah, an obligation, to visit the sick patient. This obligation, carried by all Jews, (not just rabbis or chaplains) is termed "*bikur cholim*." This obligation follows the example set by God, in Genesis 18:1, "Adonai appeared to him (Abraham) by the terebinths of Mamre; he was sitting at the entrance of the tent as the day grew hot."[33] The understanding of the rabbis is that since this verse directly follows the previous verse, where Abraham had circumcised himself, his son Ishmael, and the men of his household that the two events occurred consecutively. Therefore, in the opinions of the rabbis, God was paying a visit to Abraham as he recovered from his "surgery."[34] The rabbis understood that visits and the sense of being in community that accompanies visitation "takes away a sixtieth of the pain."[35]

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[33] Genesis 18:1 JPS translation

[34] Bava Metzia 86b

[35] Nedarim 39b

One of the chaplains I interviewed, Rabbi MD, serves as a hospice chaplain. They had a specific text that connects their work as a staff chaplain, with their own Judaism. It is connected to *bikur cholim,* encompassing the relationship between the afflicted one and the visitor ,who has an obligation to “raise up” the sufferer:

> “Rabbi Yoḥanan said to him: Is your suffering dear to you? Rabbi Elazar said to him: I welcome neither this suffering nor its reward. Upon hearing this, Rabbi Yoḥanan said to him: Give me your hand. Rabbi Elazar gave him his hand, and Rabbi Yoḥanan stood him up and restored him to health.”[36]

Rabbi MD found meaning in the story as it encapsulates the human connection. They use this text to illustrate the human connection and the act of being with people in some of their most difficult times of their life.[37]

Corollary to the commandment of *Pikuach nefesh,* Jewish tradition holds that we are commanded to heal those in need. These beliefs are derived from Exodus 21:18-19, “When [two] parties quarrel and one strikes the other with stone or fist, and the victim does not die but has to take to bed: if that victim then gets up and walks outdoors upon a staff, the assailant shall go unpunished—except for paying for the idleness and the cure.” The Hebrew for the cure is "וְרַפֹּא יְרַפֵּא:". The rabbis of the Talmud interpreted the doubling of the term, וְרַפֹּא יְרַפֵּא to emphasize that the afflicted individual should be “thoroughly healed.” This takes the commandment beyond “Thou shalt not kill” and commands us to intervene, in order to save a life.[38] We may not watch idly while someone is dying if we have the power to heal that individual. To withhold treatment is regarded as someone who has shed the blood of his

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[36] Berakhot 5b, Babylonian Talmud

[37] Rabbi MD. "Perspectives on Jewish Palliative Care Chaplaincy." By Edith Yakutis (September 9, 2022).

[38] Yoreh De’ah 336:1

brother - שופך דמים, referring to the statement made by God to Noah after the flood, "Whoever sheds human blood, by human [hands] shall that one's blood be shed; For in the image of God was humankind made.[39]

From the commandments of *Pikuach nefesh*, *bikur cholim* and healing, we will move on to address the question of whether taking medicine, or following a doctor's orders are fundamentally required of a patient, as part of healing. This is a valid consideration, especially in contemporary times, when there can be conflicting opinions and multiple options, regarding treatment of chronic illness. Jewish texts have a framework for decision-making on the part of the patient, their family and their medical team. The *Shulchan Arukh*, (Set Table, translated literally) is a book compiled and published in Venice in 1565. This book and a later gloss are often taken together, and are arguably the most widely accepted code of Jewish law written. It was compiled as a simplified interpretation of *halakhic* (Jewish law) rulings. In response to the question of medicine or medical treatment as a requirement, the *Shulchan Aruch* gives insight. The patient does have options, regarding following their doctors' recommendations. The original text addresses the question of whether a sick person must eat, or not eat, on Yom Kippur, which is a day where Jews are commanded to fast and afflict themselves as part of atonement for the wrongs they have committed in the past year:

> "A sick person who needs to eat, if there is an expert doctor there, even if he is a non-Jew, who says that if this person is not fed because it is possible that **the illness will worsen on him and he will be in danger, they feed him on the doctor's orders**, and he does not have to say that he does not need (the food) we still listen to the doctor, **but if the sick person says, "I need (the nourishment)," even if one hundred doctors say that he does not need (the nourishment) we listen to the ill person."[40]**

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[39] JPS Tanakh, Genesis 9:6

[40] *Shulchan Aruch Orach Chayim* 618:1

This is evidence that Jewish law attends to both the health professional and the sick person, ultimately choosing whichever view most saves life or health for the individual.[41] This response has been applied to days less holy than Yom Kippur, regarding a patient's autonomy regarding healthcare choices. The question of food, in this argument, is applied to medicine. Contemporary Jewish thought reasons that just as food is a requirement to preserve life, medicine can also be viewed as the same. The *Shulchan Aruch*, however goes on further, to nuance the argument about "mandatory medicine", making it appear that the patient's wishes could be overruled:

> "If two (doctors) say that he (the sick person) needs (food) and even if one hundred (doctors) say that he does not need (food) even if the sick person agrees with them (who say) he does not need (the food**) we feed him since two say that he does need (the food)."[42]**

When there is doubt of a medicine's efficacy, the patient and medical caregivers are instructed to err on the side of preserving life.

Let us return to the concept that all life is precious and how that might apply to chronic and life-limiting illness. The rabbis also knew, and accepted, that the cycle of human life is finite and that we will all cease to exist. Jewish tradition defined a graduated steps for the states of existence between life and death, as we age and/or approach end of life. As death approaches, three such states were identified: the "גוסס"   "טרפה" and הַחוֹלֶה הַנּוֹאָשׁ".
Keeping in mind the rabbis did not have access to the advanced medical care available today,

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[41] Dr. Mark Washofsky, TAL 536 class lecture notes, February 2022
[42] Shulchan Aruch Orach Chayim 618.4

we read these foundational texts for guidance on the practical application of showing respect for humanity, especially in the final phases of life.

The first state of the "beginning of the end" for one who has a chronic illness is חוֹלֶה-הַנּוֹאָשׁ. This the term for an individual who is diagnosed as having a terminal condition, without hope or recovery, but the timetable for their death is unsure.[43] They are not yet within their final year of life. As the illness progresses, a patient is considered טרפה if they are afflicted with a chronic disease and likely to die within a year.[44] The final stage of life, גוסס is for individuals considered to be "actively" dying, or imminent, within days or hours. There is rabbinic guidance for each of these states of existence. The overarching regulation, however, is that one does not hasten death in any of the situations. The rabbis in Talmud forbade even closing the eyes of a גוסס , as that is considered to be hastening their death. Euthanasia, medically hastening death, is considered murder.[45] All sparks of life within a person, however fragile, are sacred. However, options for medical treatment vary with each state of existence, which I will cover, below. Each state of existence has health and time-limited boundaries, and the patient has a voice in determining their treatments, as we read, above. An informed chaplain can draw upon these texts to advise a Jewish patient and their family, as they move their states of existence and make decisions regarding their goals of care.

At the very end of life, a person reaches the state of dying termed גוסס. The individual is actively dying, with death expected within three days. Medical treatment for the

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[43] Shemirat HaLashon, Book 1, The Gate of Discerning 15, 1875.

[44] Sanhedrin 78a

[45] Mishnah Shabbat 23:5

person who has reached the state is limited to palliative only – keeping the patient comfortable, and at a minimum, pain-free. Respect for that patient's remaining life is still paramount. The *Shulchan Arukh* covers the treatment of a גוסס in great detail. No matter how frail, the patient is to be treated as a fully living person. However, because there is no cure for this patient, therapeutic medical treatment is forbidden. There is nothing therapeutic than can be done for the person. Further treatments to try to extend life in this case is considered cruel. While the patient should not be moved, or touched, lest death be hastened, the patient is never to be left alone, as 'it is considered wrong to allow a person to die alone."[46] The *Shulchan Arukh* outlines the respect still due a person in this state; the family should not be making funeral arrangements while the patient still lives, neither should the family be rending garments or "bringing in a coffin."[47]

While there is no obligation to delay the death of a גוסס,[48] the *Shulchan Arukh* is clear the impediments to death are to be removed,

> "However, if there is anything that causes a hindrance to the departure of the soul e.g. near that house there is a knocking sound (a woodcutter) or there is salt on his tongue, and these hinder the departure of the soul, it is permitted to remove it therefrom, for there is no direct act involved in this, since he merely removes the hindrance."[49]

This guidance, given in late Renaissance times, was interpreted as a command to stop therapeutic treatments, as the natural culmination of life proceeds. We'll review contemporary interpretations of this passage in the next portion of this chapter.

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[46] Yoreh Deah 339:1

[47] IBID

[48] Levin, J. S., Prince, M. F., & Teutsch, D. A. (2013). An Overview of Jewish Bioethics. In *Judaism and health: A handbook of practical, professional, and scholarly resources* (pp. 20–37). essay, Jewish Lights Publishing.

[49] Yoreh Deah 339.1

For an individual whose terminal condition whose illness has not advanced to the state of a גוסס, yet knows that there is approximately a year of life, is considered to be in the state of טרפה. Many readers would associate “*terefah*” in the context of kashrut – the type of animal which may not be eaten by halakhic Jews. However, this term is also used in Talmud in the context of the laws on treatment of one with a chronic and life limiting illness. We read in the Talmud that the that the legal status of טרפה is that of a dead person, going to far as to note that,

> “All concede in a case where one kills an individual dying from an illness caused at the hand of Heaven (טרפה) that he (the person who killed the sick person) is not liable, as no other individual took action contributing to his death…”[50]

The טרפה therefore has a different legal status than someone who is not terminally ill. In the medical field, rabbis have historically extrapolated from that statement that because of that different status – where the individual is already living with a death sentence, that mandatory therapeutic treatments can be further reduced, if the patient and their doctor agree. While the patient could be expected to do everything possible to preserve and extend their life, as things near the end, the patient is no longer required to do so. The approach is echoed in contemporary times. Rabbi, author and bioethicist, Elliot Dorff, chairs the Rabbinical Assembly’s Committee on Jewish Law and Standards. One of Rabbi Dorff’s responsa is frequently referenced in cases of long-term but fatal illness. He wrote that a person with:

> “an incurable trauma to vital organs or a terminal, incurable disease (a terefah), patients and doctors have permission to withhold or withdraw drugs and

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[50] Sanhedrin 78a.

> machines, if it is in the patient’s best interests. He also instructed that in all cases, comfort care (palliation) must be administered.”[51]

One of the few mentions in the Talmud of “Palliative” or non-therapeutic care is found in *Ketubot* 103b and 104a. There is a brief reference of a “palliative treatment” for the seriously ill. When Rabbi Yehuda HaNasi was ill, he was “transferred to Tzippori, which is situated at a high altitude and the air is scented…” Given the HaNasi was physically moved, we know he was not considered a גוסס, at the time. Taking him to Tzippori, a beautiful village, might be considered something like a palliative treatment. Moving the patient to a more pleasant place, even as their health deteriorates, could contribute to the patient’s remaining time alive more pleasant. While this receives barely a passing comment, it is an indicator that the rabbis were aware of and concerned with the comfort of a patient.

The term for an individual who is diagnosed as having a terminal condition is חוֹלֶה הַנּוֹאָשׁ. The individual is without hope of recovery, but the timetable for their death is unsure. They are not yet within their final year of life. The condition of being חוֹלֶה הַנּוֹאָשׁ, literally, “desperate patient,”[52] is not directly addressed in Talmudic literature, nor commentary of the Middle Ages or earlier. This is likely because the state of being a חוֹלֶה הַנּוֹאָשׁ would have been rarer. This is unlike contemporary times which has seen the rise of individuals experiencing longer periods of chronic illness. The first appearance of the term is found in “*Shemirat HaLashon*”, published in 1875, by Lithuanian rabbi, Israel Meir Kagan. It was

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[51] Dorff, Elliot N. Matters of Life and Death. Jewish Publication Society, 2003.

[52] Sometimes translated at “hopeless patient”

Kagan’s stance that the חוֹלֶה הַנּוֹאָשׁ would be obligated to seek medical cure, to prolong his life,

> “Would **he (the desperate patient)** hesitate to send immediately for this doctor to come and see him in his suffering on his sickbed in the hope that he might cure him of his illness? And if one of his loved ones would ask him: "Why are you more zealous than others?" would he not answer: "Fool, where my life is at stake, I would not look at others even if there were a possibility of a possibility [that I might be saved]! How much more so with this doctor, whom we know, ourselves, from the past and who is universally renowned for his awesome cures of all **desperate illnesses**, would I abandon my life for the sake of these fools who have no mercy on *their* lives?"[53]

From this description, we read that it would be expected for a patient with a newly diagnosed chronic illness to urgently seek out medical advice.

From the texts selected here, we understand that a Jew is obligated to choose life for themselves, as long as possible. And we understand that the rabbis were aware that eventually, therapeutic medicine will lose its efficacy, and that the outcome of all life, is eventually death. Their guidance was to make this transition as painless as possible.

Contemporary Jewish Values and Guidance for Healthcare of the Chronically Ill

This portion of the chapter covering Jewish texts, will address current Jewish guidance for individuals living with chronic illness. Lifespans have increased greatly since 500CE when the Talmud was compiled. As we can see in this table from the Social Security actuarial tables, since the last century, Americans have begun to live much longer.

Birth Year	Female	Male
1900	50	46

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[53] Shemirat HaLashon, Book 1, The Gate of Discerning 15, 1875

1960	74	66
2019	81.18	76.22

Life Expectancy Table 3.1[54]

In 2015, approximately seventy percent of the individuals over the age of 70 needed some form of support. By 2050, the forecast is that over 27 million Americans will need longer term medical care.[55] Contemporary medical treatments are expanding the length of time that a patient lives, even with a chronic or terminal illness. This “aging boom” may represent a crisis for long-term care. It also represents a blessing, with an opportunity examine how we can age, and better attend to a person’s spiritual needs. Just as the baby boom represented an opportunity for growth and change, the corresponding echo of the elder boom offers the same.

As noted earlier in this document, while there is scant content regarding instruction for end-of-life discussions and recommendations for curative treatment for the טרפה. There is even less written in the Talmud regarding the treatment of someone considered חוֹלֶה הַנּוֹאָשׁ, or “the desperate patient.” This individual has a chronic or terminal illness. While the timetable for their death from the illness is unknown, it is considered to be longer than a year. Perhaps so little is written in Talmud on this because at the time the it was written and compiled, life was more uncertain, and death came sooner for most individuals. Therapeutic treatments were less efficacious at prolonging life. Lingering deaths would have been rare. Contemporary times have seen a sharp rise in the numbers of individuals in the state of חוֹלֶה

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[54] Source: https://www.ssa.gov/oact/NOTES/as120/LifeTables_Body.html

[55] Poo, Ai-jen. The Age of Dignity: Preparing for the Elder Boom in a Changing America. New York City, NY: The New Press, 2016.

הַנּוֹאָשׁ, as medical knowledge has led to earlier detection of chronic illness, and medicines with better potentially curative and life-extending treatments.

Jewish thought has been confronted with new challenges when addressing chronic illness, long before death nears the patient. There are ever increasing number of individuals who live in the state of being a חוֹלֶה הַנּוֹאָשׁ, or an individual living with a terminal illness. This has given rise to concerns on what would be considered a mandatory medical treatment, as opposed to merely permitted, or allowable treatment, which was reviewed earlier in this chapter. The emphasis in Jewish law on preserving life causes a deep aversion against anything that could be perceived as euthanasia, or suicide. This section of the thesis gives an overview of recent thought, in order to inform the Jewish chaplain who is often in the position of "translator" between patients, families and medical caregivers.

Rabbi Immanuel Jakobovits[56] determined that the rules around extending life for an individual who has reached the state of חוֹלֶה הַנּוֹאָשׁ are nuanced. Given that חוֹלֶה הַנּוֹאָשׁ has no hope of a full medical recovery, and yet may live longer than a year, Jakobovits notes a wider range of medical choices for this individual. For example, an individual with type 1, insulin-dependent diabetes, must take insulin, as it is expected to prolong their life. While the insulin cannot cure diabetes, it is therapeutic, and is reasonably expected to keep the patient healthy over many years. People with well-managed type 1 diabetes can be expected to live fairly normal lifespans. If the patient were to stop taking insulin, however, they would develop diabetic ketoacidosis which, untreated, leads to death. Therefore, the patient must take insulin, to preserve their life. This is consistent with older rabbinic guidance, regarding

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[56] Chief Rabbi of the United Hebrew Congregations of the British Commonwealth, an authority on Jewish medical ethics and member of the House of Lords. Born 1921, died 1999.

"mandatory medicine". However, if that patient should also develop an inoperable, terminal cancer, they would be considered to be חוֹלֶה הַנּוֹאָש. The cancer will kill the patient within a few years and greatly increase their pain during that time. According to Rabbi Jakobovits, there should be no objection, should that individual choose to discontinue their insulin regime. Because of the cancer, there is no treatment that will sustain this patient, nor return the patient to their healthy state of well-managed diabetes. In this individual's case, continuing to take insulin could be considered to be impeding death. Therefore, cessation of the insulin regime would be permitted. Jakobovits determined that:

> "…Jewish law sanctions (permits) the withdrawal of anyt factor – whether extraneous to the patient himself or not, which may artificially delay his demise in the final phase."[57]

Rabbi Jakobovits' viewpoint seems to take into account the life of the whole person, not just the illnesses afflicting the person.

Pain management is a critical aspect of palliative care. There is very little written in Talmud about addressing pain. Many contemporary observant Jews express reluctance to use narcotics to lessen agonizing pain, citing the concern that the pain medications themselves may shorten life, which is expressly forbidden. There are numerous contemporary Responsa on the topic. In the Talmud, *Ketubot* 104a provides justification for providing pain medications. Rabbi Judah HaNasi was dying in great pain. Rabbis and students had gathered around and were praying that Rabbi Judah would not die. Their prayers were causing Rabbi Judah to remain alive, but in agony. Rabbi Judah's maidservant saw that amount of pain he was in, and smashed a pot, the sound of which interrupted the rabbis' prayers, allowing

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[57] Jakobovits, Immanuel. Jewish Medical Ethics. New York City: Bloch, 1975.

Rabbi Judah to die, ending his agony. This source is often cited as permission to act on behalf of a terminal patient, to relieve their pain, even if it might shorten their life.[58]

In more contemporary times, Reform Jewish rabbi and former chair of the Responsa Committee of the CCAR also addressed pain management, along similar lines,

> "Halakhic insistence on the inviolability of human life is balanced, and at times outweighed, by its concern for the alleviation of human suffering. Thus, patients are allowed to undergo risky surgery to relieve severe pain, even though the operation places them in mortal danger… a physician may administer a powerful dose of morphine, even when the drug may shorten the patient's life, for pain itself is seen as a disease deserving of treatment."[59]

We may take no active steps to terminate life, have no duty to prolong the process of dying, if the patient is in great pain.

A third rationale which a chaplain can cite regarding palliative pain treatment addresses that topic of pain as its own disease. This knowledge may be helpful to a patient and their family, as they consider their goals of care and their Jewish values. In Jewish law, a person in physical agony is not considered a "free agent", but under unfair compulsion, which allows for another perspective in treatment of pain. In general, Judaism is not an ascetic tradition and does not advocate for any type of self-affliction through pain. The only real exception for enduring pain and discomfort would be *Yom Kippur* and other fast days.[60] In the late twentieth century, Rabbi Eliezer Waldenburg, served as a rabbi and judge (*posek)* on the Supreme Rabbinical Court of Jerusalem. He was an authority on medicine and

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[58] https://www.ccarnet.org/ccar-responsa/rrt-84-89/

[59] Washofsky, Mark. "Nancy Cruzan and the Right to Die." Midwest Medical Ethics, Fall (1990).

[60] Jacob, Walter. *Questions and Reform Jewish Answers.* New York City, NY: CCAR, 1992. P. 23

halakha. His writing, the *Tzitz Eliezer* published in 1973 adds additional justification for pain management:

> “Regarding a dangerously-ill person of whose healing the doctors have given up hope, and suffers tremendously from his illness, may one increase the amount of pain reduction medicine, such as morphine, despite the fact that they do not heal the illness and might even hasten his death.
> It appears to me that anywhere the medicines are given by the doctor, whether in pill form or intravenously, in order to lessen the pain, one may give it to the patient. Even though they might hasten his death, this too is included in the category of permission that was given to doctors to heal...”[61]

From these contemporary writings, we can understand that judicious use of pain medications is certainly permitted, by current Jewish interpretation of the laws. As part of goal of care, the patient should be kept free of side-effects and extreme pain as much as possible throughout their illness. The informed Jewish chaplain working with a Jewish patient can draw upon these texts above, as items for thought, in the medical decision-making process.

CHAPTER 4: PALLIATIVE CARE AND HOSPICE, HISTORY AND CURRENT STATE

This chapter will trace the beginnings of hospice and palliative care, as well as how funding and patient population differentiates between the two. The informed chaplain can assist the patient and their family in understanding their options as they reflect upon their treatment options.

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[61] Waldenberg, Eliezer (1973). Shu"t Tzitz Eliezer: vol. 11 (in Hebrew). Jerusalem. p. 41

Medical History of Hospice and Palliative Care

As noted earlier, palliative care and hospice care are often conflated. Hospice care is a specific type of palliative care, the way a Honda is a specific type of automobile. All hospice care is palliative, but not all palliative care is hospice care. That being written, hospice and palliative care share a common history. Both work with chronically ill people facing life-limiting illnesses. The concept of professionalized care, however, is a development in the past 150 years, as care of the chronically ill moved from home and family into different settings. The distinct medical specialty of non-curative symptom palliation for patients is a relatively recent development.

The term "palliative care" was first coined by Canadian surgeon Dr. Balfour Mount in the early 1970's.[62] He used the contemporary term "palliation" and was including the meaning of the word referenced in the terminology section - as something of a cloak, or shield. Palliative care was meant to shield the patient from the symptoms of their illness. By 1987, palliative medicine was recognized as an area of specialty in the UK. The US followed suit much later, recognizing palliative care as a medical sub-specialty in 2006. To understand this process, we need to review the history.

In the nineteenth century, long-term, prolonged illness was becoming a reality. Western society was encountering increasing numbers of lingering deaths, caused by tuberculosis and cancers. This was a change, far different from previous centuries. Prior to the Industrial Age,

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[62] Clark, David. *To Comfort Always: A History of Palliative Medicine since the Nineteenth Century.* Oxford: OUP Oxford; Illustrated edition, 2016. P. 106

the majority of deaths were caused by disaster, infection, or disease.[63] Medicine, in general, is devoted to working with sick individuals, with the goal of their recovery and a return to normal life. When there is no chance for the patient to recover, medical doctors and healthcare workers historically have moved on, shifting their focus on other patients who were perceived to have a chance of recovery. What then happened to the terminally ill patients, now left with no medical care and no space in a hospital?

As terminal illness duration lengthened, growing numbers of individuals were in need of care for longer periods of time, as their health declined. Wealthy and middle-class patients may have had financial resources and family to provide care. Patients in the lower and less monied classes were not so fortunate. These were the patients in greatest need of ‘hospitality’ and hospice, as their end of life neared. A cobbled-together patchwork of groups caring for the chronically ill and dying began to develop as an informal, Church-based network, with scant medical care and pain management. True to its beginnings, initially hospice was often faith-based and Christian.

A medical doctor, William Munk, took a different approach to the concept of “moving on”, when his patients became terminally ill. He was an American general practitioner living in the nineteenth century. He wanted to assist his patients in their final months. In 1887 he published a book titled, “Euthanasia: Or Medical treatment in aid of an easy death” in which he highlighted the original definition of euthanasia, having nothing to with a medically hastened end of life. Munk epitomized the older definition prevalent in his era, which is that

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[63] Clark, David. *To Comfort Always: A History of Palliative Medicine since the Nineteenth Century.* Oxford: OUP Oxford; Illustrated edition, 2016. P. 5

euthanasia was a “idealized easy death.”[64] Dr. Munk was a vocal advocate that physicians, in addition to nurses and family, should remain with the patient, providing medical management for pain management as well as other symptoms that arise, as the body dies. He was also aware that many patients also sought spiritual care, as death approached and that the physician should step back to allow for that care to be provided. Munk also wrote emphatically that there should be no medical hastening of death for the patient. His views were popular, and he gave frequent lectures. After his death, however, medical interest in palliative care, and research on end-of-life care waned. The field was left to general or family practitioners and families. There was little published, even as curative medicine made great strides.

In 1925, there began to be a resurgence of medical interest in chronic illness and end-of-life care, with the medical, spiritual and socials needs it represented. Dr Alfred Worcester a Harvard trained medical doctor was appointed Professor of Hygiene at Harvard. He gave number of lectures on the topic of geriatrics and care of the dying, which became a book, and gained widespread use for the medical audience who had never met him in person. Worcester wrote,

> “Normal babies can be cared for by the wholesale; not so old men and women. They need individual attention; no two cases are alike. Moreover, the treatment suitable for younger patients becomes progressively unsuitable for the aged. Their comfort, and not their impossible rejuvenation should be the physician’s aim.”[65]

Worcester’s lectures and printed booklet were followed by Dame Cicely Saunders’ work to normalize and professionalize a team approach to care of the dying. Saunders is arguably

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[64] Clark, David. *To Comfort Always: A History of Palliative Medicine since the Nineteenth Century.* Oxford: OUP Oxford; Illustrated edition, 2016. Page 199

[65] Worchester, Alfred. *The Care of the Aged, the Dying and the Dead.* Springfield. IL: Charles C. Thomas, 1935.

one of the founders of a more holistic and professionalized approach to hospice and dying, with spiritual care and management of symptoms performed alongside medical care. She advocated that “humans should be able to die with dignity and at peace.”[66]

Saunders started her career as a nurse, training at London’s St. Thomas Hospital. After an injury precluded her nursing career, she transitioned to become a medical social worker. A lifelong learner, she then trained as a medical doctor, achieving board certification in 1957, developing her interest in providing better care to those with terminal illnesses.

Saunders’ interest in palliative medicine and hospice care began in the late 1940’s when she was working at the London Hospital. There, Saunders learned principles of pain relief and began to formulate her beliefs on chronic, terminal illnesses. As she was finishing her medical studies in the 1950’s, she wrote a thorough paper on care for the dying titled, “Dying of Cancer”, published in the St. Thomas’s Hospital Gazette. This paper is frequently referred to as the first comprehensive examination of issues which still confront the chronically ill and their caretakers, today: nursing, pain, mental distress and more. In the paper, she began to explore the concept of dedicated homes or spaces for terminal patients, with specially trained staff dedicated to assisting the patient and their family, medically and spiritually. Core to Saunders approach to palliative care is the treatment of “total pain”, which she defined as the suffering that “encompasses all of a person's physical, psychological, social, spiritual, and practical struggles.”[67] Saunders took a holistic view of end of life, based on three principles: pain control, a family or community environment, and engagement with the dying person’s

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[66] *Spirituality in Hospice Palliative Care.* Edited by Paul Bradamat. Albany, NY: State University of New York, 2013.

[67] Ong CK, Forbes D. Embracing Cicely Saunders's concept of total pain. BMJ. 2005 Sep 10;331(7516):576. doi: 10.1136/bmj.331.7516.576-d. PMID: 16150775; PMCID: PMC1200625.

spirituality. Her consistent stance was that that spiritual care is an intrinsic component to treatment.[68]

Saunders continued to develop her ideas, circulating her writing to a group of associates, with the idea of opening a “modern” terminal care home. She worked with doctors, lawyers, and theologians in the shaping of a hospice community, which eventually opened in 1967, as St. Christopher’s Hospice. The name was deliberately chosen to recall St. Christopher as the patron saint of travelers. The Hospice, while independent from a church organization, was rooted in Christian faith. St Christopher’s is still serving patients today. It has consistently had full-time chaplains on staff, and works in coordination with “clergy and faith leaders across the community.”[69]

Dame Saunders’ numerous academic lectures and publications on the topics of palliation sparked solid interest in address this need, globally. A team of colleagues who were passionate about supporting individuals with chronic and terminal illnesses expanded the field of palliation and end of life care, following her precepts. The field continues to develop and professionalize.

Development of US Formalized Hospice and Palliative Care

In the US, palliation was developing along parallel lines, but more slowly. In 1873, the United States had approximately 120 hospitals. Those hospitals were reserved for the sick and injured, not terminal patients. Individuals who were actively dying largely excluded from

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[68] Saunders, C.M. Appropriate treatment, appropriate death. In *Management of Terminal Malignant Disease*; Saunders, C.M., Ed.; Edward Arnold: London, UK, 1984; pp. 1–16.

[69] https://www.stchristophers.org.uk/service/spiritual-and-emotional-support/

care.[70] Care of the terminally ill was generally the responsibility of the patient's family. Care of the dying was expected to be provided at home. While there were American Medical Association (AMA) guidelines in the mid-18th century urging doctors not to abandon patients once a cure was no longer possible, physicians were "largely absent from the deathbed."[71] If they had no home, or family, the workhouse was the last resort. Unlike Great Britain, hospice as a term, and a place for terminally ill individuals spend their last days was virtually unknown in the US.

It was not until after Dame Cicely Saunders spoke about her vision for hospice care at Yale University in 1963 that the hospice movement began to gain momentum in the US.[72] An attendee to Saunders' lecture was Florence Wald, who served as Associate Professor and Dean of the Mental Health and Psychiatric Nursing at Yale. Between Saunders' lecture and Wald's experiences as a practitioner, she was inspired to learn more. In a later interview, Wald noted, "In those days the (terminal) patient went through hell and their family was never involved."[73] Wald wanted to change that. She took a sabbatical from her position at Yale and travelled to England. Wald and Saunders began working together on approaches of palliative care and care of the dying. Wald worked at St. Christopher's, when it opened in 1967. Upon her return to the United States, Wald assembled her own interdisciplinary team of doctors, clergy, and nurses to study the needs of dying patients.

Wald's goals of opening a dedicated hospice facility in the US was likely aided by Elisabeth Kubler-Ross' book, "On Death and Dying," which was published in 1969, after St.

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[70] Clark, David. *To Comfort Always: A History of Palliative Medicine since the Nineteenth Century.* Oxford: OUP Oxford; Illustrated edition, 2016. Page 9
[71] Clark, David. *To Comfort Always: A History of Palliative Medicine since the Nineteenth Century.* Oxford: OUP Oxford; Illustrated edition, 2016. P.9
[72] https://www.nhpco.org/hospice-care-overview/history-of-hospice/
[73] https://www.hospice.com

Christopher's Hospice opened in England. The book created a shock wave, as medical and lay readers absorbed the data presented: descriptions of the steps through which the terminally ill process their own mortality. Prior to this book coming onto the market, conversations around death and dying were more or less taboo, and the medical culture of the times was highly authoritarian. The patient's wishes and experiences were often given little weight in the plan of care devised by the medical team. Kubler-Ross had researched the dying process by interviewing numerous terminally ill patients. Her book has become the most taught model for understanding a patient's psychological reactions to confronting their imminent death. This book began to change the conversations about death and dying, both in the lay and medical cultures.[74] Death, as an outcome of serious, chronic illness, could be discussed more openly, including a spiritual approach for experiencing a "good death."

Wald utilized Kubler-Ross' work, and coupled it with her own, as she continued working toward a dedicated hospice facility to provide for terminally ill patients in the US. In 1974, "Connecticut Hospice," was opened, in Branford Connecticut. The initial staff was comprised of two pediatricians, a nurse, and a chaplain. That same year, there was also legislation introduced to provide federal funding to recipients of hospice care, however it was not enacted.[75] It was not until 1983 that hospice care became a "covered", or reimbursable medical service, paid for by Medicare, Medicaid, and private insurance. Single-payer method of funding hospice made it more accessible to patients.

We need to have a brief aside regarding the American medical payment system. Medicine in the United States is unlike many other countries. The US has developed separate

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[74] Tyrrell P, Harberger S, Schoo C, et al. Kubler-Ross Stages of Dying and Subsequent Models of Grief. [Updated 2022 Nov 19]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan/

[75] https://www.nhpco.org/hospice-care-overview/history-of-hospice/

insurance and payer systems. As a note, however, even with medical insurance, healthcare can be largely unaffordable for most American citizens.[76] Individuals without private or public insurance are often charged higher rates by hospitals.[77] The problems and solutions of American healthcare and its funding are a topic for a different paper.

Hospice care, as a Medicare/Medicaid benefit, has qualification criteria defined by insurance companies, in conjunction with the federal programs including Medicare, Medicaid, and the Department of Veterans Affairs. Currently, patients meet the criteria for insurance coverage of hospice, if their life expectancy is considered to be less than six months, and the patient agrees to forego all further therapeutic treatment.[78] If patient meets those criteria, they can "enter hospice," and expect that the majority of their expenses will be covered. Hospice organizations or agencies serve these patients, either in facilities or the patient's home. The organizations and agencies are subject to Centers for Medicare and Medicaid regulatory requirements. Those requirements mandate that the patient be provided medical, psycho-social, and spiritual care, with the intention to make the patient and their family as physically and emotionally comfortable as possible.[79]

After hospice care became an eligible benefit, a largely separate system of care for the terminally ill grew. Before the Medicare hospice benefit was enacted in 1983, the National Hospice Organization estimated that there were less than 200 hospice agencies who could meet the regulatory requirements legislated.[80] The CDC estimates that as of 2018, there

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[76] Pew https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2022/10/07/many-patients-cant-afford-health-costs-even-with-insurance

[77] https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/.

[78] Amy S. Kelley, M.D., M.S.H.S., and R. Sean Morrison, M.D. "Palliative Care for the Seriously Ill." *New England Journal of Medicine* 373 (2015).

[79] https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice

[80] Davis FA. Medicare hospice benefit: early program experiences. Health Care Finance Rev. 1988 Summer;9(4):99-111. PMID: 10312635; PMCID: PMC4192888.

were 4,700 hospice care agencies.[81] As the US population ages, the hospice industry will only continue to grow. In 2021, hospice agencies represented a $23 billion industry, and 20% of the US home-based care market. This growth in services is matched by a growth in demand. Hospice agencies in every market have job listings for chaplains, to provide spiritual care for their patients.

US Palliative care

This portion of the chapter four will address the increasing differentiation between palliative and hospice care. As we have read, palliative medical care arose with hospice care, in both the US and the UK. It provides a humanistic approach to health care, which means that the patient is seen, and treated, as a person, with a story, beliefs and deserving of respect and dignity, not only a collection of symptoms to be addressed. Palliative care is as much about the patient living a quality life as they define it, as it is about symptom management.[82] As the value of palliative care was recognized for patients whose illnesses were not terminal, palliative care has necessarily evolved into its own related specialty. Both hospice and palliative care were recognized as a subspeciality by the American Board of Medical Specialties in 2006.[83]

The chart from the New England Journal of Medicine (NEJM) below outlines the differences between hospice and palliative care.[84] While the teams for both types of care are interdisciplinary, hospice care focuses on the patient and their family at the end of their life.

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[81] https://www.cdc.gov/nchs/fastats/hospice-care.html

[82] Rabbi Edith Meyerson, Ph.D. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (August 23, 2022).

[83] https://aahpm.org/

[84] Kelley, Amy S., and R. Sean Morrison. "Palliative Care for the Seriously Ill." New England Journal of Medicine 373, no. 8 (2015): 747-55.

There are no further therapeutic treatments. The goals for both specialties are an improved quality of life, and ideally, there is meaningful spiritual care provided to support the patient and their family. Hospice care provides the added focus on relieving spiritual, physical and emotional suffering. Patients are only eligible for hospice care if they are deemed to be in the last six months of their life. This is in contrast with palliative care, which interacts with primary care and therapeutic care teams as well. You can read more on the "Eligibility" characteristic of palliative care.

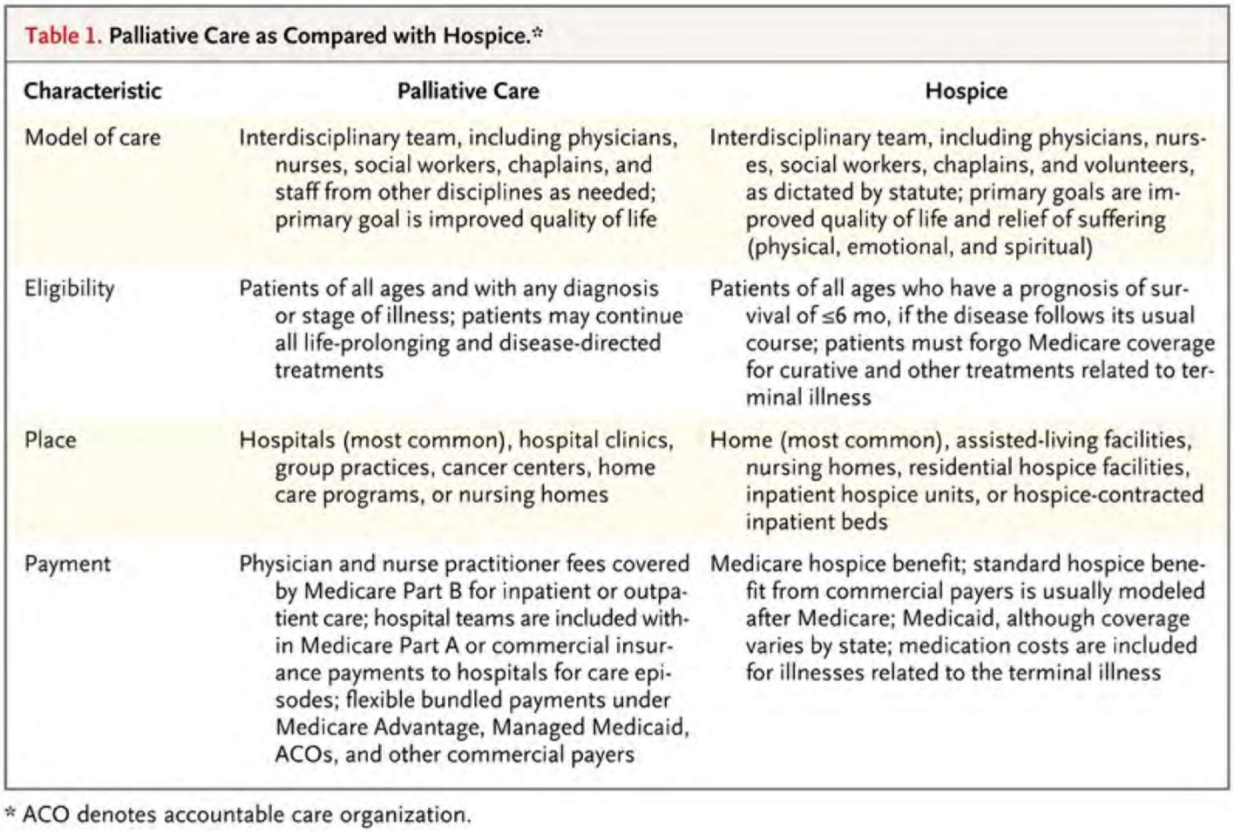

Table 1. Palliative Care as Compared with Hospice.*

Characteristic	Palliative Care	Hospice
Model of care	Interdisciplinary team, including physicians, nurses, social workers, chaplains, and staff from other disciplines as needed; primary goal is improved quality of life	Interdisciplinary team, including physicians, nurses, social workers, chaplains, and volunteers, as dictated by statute; primary goals are improved quality of life and relief of suffering (physical, emotional, and spiritual)
Eligibility	Patients of all ages and with any diagnosis or stage of illness; patients may continue all life-prolonging and disease-directed treatments	Patients of all ages who have a prognosis of survival of ≤6 mo, if the disease follows its usual course; patients must forgo Medicare coverage for curative and other treatments related to terminal illness
Place	Hospitals (most common), hospital clinics, group practices, cancer centers, home care programs, or nursing homes	Home (most common), assisted-living facilities, nursing homes, residential hospice facilities, inpatient hospice units, or hospice-contracted inpatient beds
Payment	Physician and nurse practitioner fees covered by Medicare Part B for inpatient or outpatient care; hospital teams are included within Medicare Part A or commercial insurance payments to hospitals for care episodes; flexible bundled payments under Medicare Advantage, Managed Medicaid, ACOs, and other commercial payers	Medicare hospice benefit; standard hospice benefit from commercial payers is usually modeled after Medicare; Medicaid, although coverage varies by state; medication costs are included for illnesses related to the terminal illness

* ACO denotes accountable care organization.

Ideally, palliative care would begin at the same time as any diagnosis of serious, life-threatening, or chronic illness. Palliative care would continue in coordination with therapeutic treatments. This co-ordination of treatment for symptoms, psychological and/or spiritual distress provides a more thorough level of support for the family.

Ongoing research indicates that patients wish to have a discussion of their spiritual or existential concerns. These discussions allow the patient to acknowledge their beliefs hopes and plans for their life, outside of their illness. Unfortunately, few physicians and medical healthcare providers believe it is it their role to conduct that conversation.[85] In a way, the oncologist is “just” a doctor for cancer, not the spirit, or psyche of a patient. Medical staff are not trained for interventions of the spirit. This can leave the patient adrift in a foreign world full of medical jargon, which in no way relates to their existential questions.

Another crucial difference outlined in the NEJM table above is in the manner of payment. Hospice is a clearly defined benefit, as a single unit of payment through Medicare, Medicaid, and the insurance system. The broader specialty of palliative care is not a “single unit” of care, currently. For the patient to receive palliative care at this time, a wider combination of insurance billing codes is required. This can have the impact of limiting access to the wider range of support available to a patient with chronic illness, especially if the primary care physician is reluctant to engage the palliative team. Therefore, this requires greater coordination and cooperation between medical specialty teams within the healthcare setting.

The table below represents the interdisciplinary approach to patient engagement provided by palliative care.[86] There are separate spheres, or domains, all focused on the patient and their family. This chart shows both the promise of humanistic, “whole patient” care, and also the potential shortcomings of the medical payment system spread across those

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[85] Kelley, Amy S., and R. Sean Morrison. "Palliative Care for the Seriously Ill." New England Journal of Medicine 373, no. 8 (2015): 747-55.

[86] Palliative Care; a Guide for Health Social Workers. Edited by M.L. Leimena and T. Altilio B. Sumser. New York, NY: Oxford University Press, 2019.

different groups, from the physical aspects of care, through the social work system, and spiritual care.

Domain	Aspect of Care	Components
1	Structure and Process of Care	Interdisciplinary team, Comprehensive interdisciplinary assessment, education and training, teamwork/structure, care planning, continuity through transitions, relationship with hospice program
2	Physical aspects of care	Diagnosis, symptom management, medications, multidimensional interventions
3	Psychological and psychiatric aspects of care	Mental health (anxiety, depression, delirium), adjustment and adaptation, demoralization, coping, comorbid psychiatric illness, referral to appropriate services
4	Social	Family system and structures, changes in social role, concrete needs, financial concerns
5	Spiritual, religious and existential aspects of care	Connection to spiritual/religious meaning, ritual and community, coping mechanisms, hopes and fears, being with the unknown, resilience and awareness.
6	Cultural aspects of care	Culture-specific needs of patients and families, language, ritual, dietary, relationship to the health care system, illness and symptom-related beliefs and values, decision-making variation
7	Care of the imminently dying patient	Prognostication, illness trajectory, loss, grief and bereavement, active dying, referral to hospice when patient is eligible, funeral planning, family/caregiving needs
8	Ethical and legal	Patient’s goals form basis for plan of care. Advance directives, proxy and surrogacy decision -making, ethics committees/consultation, physician aid in dying. Team is knowledgeable about relevant federal and state laws.

Table 1[87]

Palliative care continues to develop across this structure, linking skillsets across specialties of care. The Domains, listed above are not intended as “silos”, disconnected from

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[87] *Palliative Care; a Guide for Health Social Workers.* Edited by M.L. Leimena and T. Altilio B. Sumser. New York, NY: Oxford University Press, 2019. P. 5

each other, but more as concentric circles of care, with the patient, the family and the provider team integrated in support of the patient. The chaplain would have access to the full spectrum of the patient's current state, and be able to work with the patient and their family to clarify their existential values and priorities. The chaplain, in turn is expected to provide the wider palliative team with greater understanding of the rationale for the patient/family's choices and perhaps greater cultural understanding. This model is still likely more aspirational than practiced currently, as we recall palliative care was recognized as a discipline less than two decades ago.

As we have read in this chapter, palliative care and hospice grew from the desire to provide dignity, protection, and community to people with chronic and life limiting illnesses. The field has developed and expanded its reach and is continuing to evolve.

CHAPTER 5: JEWISH CHAPLAINCY IN THE US

Chaplaincy is defined within this paper as an individual who is an ordained clergy member of a recognized faith tradition who has been accredited through a major accrediting body, to serve as a spiritual guide to individuals in times of need outside of a church or synagogue environment. This chapter will examine how chaplaincy began as a profession in the US, rather than solely an extension of congregational service and how Jewish chaplains, expanded their reach beyond the bima, creating rabbinates which support Jews (and others) where those people are. This chapter will conclude with the experiences of contemporary Jewish chaplains.

History of American Jewish Chaplaincy

Religion has always occupied a prominent role in nurturing people with spiritual needs. As noted by the etymology of the word "chaplain", it derives from the Latin, "*cappellanus*" or custodian of the cloak. Chaplaincy is a "little cape", providing cover, if only briefly, from the harsh elements buffeting a person.

Chaplains are found across the secular landscape – the military, hospitals, schools and prisons, to name a few. Chaplaincy began in the US when Episcopal minister, Reverend John Hurt, became the first official chaplain to the US Army, providing spiritual care to the 6th Virginia Regiment during the American Revolution.[88] Since then, the US Army has employed chaplains of all recognized faiths to support their troops. The US Congress has also maintained chaplains since its inception. The Continental Congress elected Jacob Duche,

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[88] The Army Chaplaincy: Professional Bulletin of the Unit Ministry Team, Department of the Army (1995), p. 32

the Rector of Christ Episcopal Church in Philadelphia as its first chaplain in 1774. After the American Revolution, the House chose William Lynn, a Presbyterian minister from Philadelphia, as its first chaplain, and the Senate selected Samuel Provost, Episcopal bishop from New York to lead them in official prayer.[89] While the US government has no officially established religion, there is a predominantly Protestant Christian outlook. While there have been "guest" chaplains, including members of the Jewish and Islamic faith, all but two congressional chaplains to date have been from the Protestant Christian tradition.

The Army was the first secular institution to accept Jews as chaplains. This was not an easy gain, however. In 1862, the American Civil War was underway. There was the patriotic desire on the part of the Jewish community to serve the Union in many capacities. However, rabbis were blocked from providing spiritual care as chaplains. Early in the American Civil War, US Congress signed the Volunteer Bill into law which was approved in July 1862. It mandated that every regimental commander appoint a chaplain for his regiment. The bill explicitly excluded Jews, outlining that the chaplain was to be "a regularly ordained minister of some Christian denomination."[90] When Rabbi Arnold Fischel of Shearith Israel, New York was appointed to the position of chaplain to a regiment, he dutifully applied for commission. The Army denied his application, following letter of the law. When his rejection became public, many Americans, including Christians, found this to be in opposition to American ideals of religious freedom. This discriminatory action by congress elicited a strong reaction, with demands that the bill be amended to substitute the word "religious" for the word "Christian." The amendment was supported by Jews and many Christians alike,

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[89] Amer, Mildred. "House and Senate Chaplains." edited by Congressional Research Service. Washington, DC, 2008.

[90] Barish, Louis. "The American Jewish Chaplaincy." American Jewish Historical Quarterly 52, no. 1 (1962): 8-24.

with 37 non-Jewish members of the Maryland legislature making a direct request to their congressman in support of the change.[91]

Newspapers added their pages in protest, as well, stating that "if no one objected when Jews volunteered for military service, then no one had the right to object to their wanting to be served by Jewish Chaplains."[92] When President Abraham Lincoln became aware of the law, he submitted a list of changes to the Congressional Committee on Military Affairs. The law was amended to include the language, "of some religious denomination," rather than Christian. It was passed in July 1862. The Jewish community had achieved what they requested over 200 years before from Peter Stuyvesant, equal opportunity to serve their country.[93]

Rabbi Fischel did not continue to pursue achieving commission as US Army Chaplain, he returned to the pulpit. Three other rabbis were commissioned, during the course of the Civil War. The first was Rabbi Jacob Frankel of Rodeph Sholom, Philadelphia, who was appointed chaplain to a military hospital by Abraham Lincoln. Rabbi Bernard Henry Gotthelf, a rabbi from Louisville, KY served in military hospitals as well.[94] Rabbi Ferdinand Sarner, the first Jewish chaplain assigned to a combat unit, and was wounded at the Battle of Gettysburg.[95]

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[91] Korn, Bertram W. "Religious Freedom in America: The Viewpoint of American Jewish History." *CrossCurrents* 13 (1963): 34-42

[92] Korn, Bertram W. "Religious Freedom in America: The Viewpoint of American Jewish History." *CrossCurrents* 13 (1963): 34-42.

[93] Slomovitz, Abraham Isaac. *The Fighting Rabbis.* New York, NY: New York University Press, 1999. P 16.

[94] Korn, Bertram W. "Religious Freedom in America: The Viewpoint of American Jewish History." *CrossCurrents* 13 (1963): 34-42.

[95] Slomovitz, Abraham Isaac. *The Fighting Rabbis.* New York, NY: New York University Press, 1999. P 20

Following the Civil War, chaplaincy expanded and evolved further into the civilian world. Jewish chaplaincy followed suit. Civilian American Jewish chaplaincy emerged alongside Jewish hospitals, protecting needy Jews from unwelcome proselytization from Christian ministers.[96] In 1861, the directors of the "Jews' Hospital" in New York invited four pulpit rabbis to tend to patients in their hospital. Rabbi Samuel Isaacs of New York was one of the four.[97] The rabbis did not seem to receive payment for their services by the hospital, instead, they rabbis were serving congregations full-time.

In addition to Jewish hospitals, rabbis also began serving in prisons and correctional facilities. While many were unpaid positions, some were funded.[98] Standardized training or certification other than rabbinic ordination, was not available. This was consistent with Christian chaplaincy.

By the 1920's, Christian faith organizations began to become more professionalized and standardize approaches to pastoral care. The Christian Protestant community developed pastoral training involving case studies, fieldwork, and clinical supervision. This course of study was labelled Clinical Pastoral Education (CPE). It was loosely organized and Christian in its viewpoints, with the majority of students being Protestant ministers and seminary students.[99]

In the Jewish world, there was no parallel standardized training developing, to serve Jews outside of the synagogue setting. College-campus based Hillels began in the 1920's,

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[96] Wendy Cadge, Bethamie Horowitz. "Mapping Jewish Chaplaincy." Chaplaincy Innovation Lab, 2022.

[97] Robert Tabak, "The Emergence of Jewish Health-Care Chaplaincy: The Professionalization of Spiritual Care," American Jewish Archives Journal 62, no. 2 (2010):

[98] Mark K. Bauman and Leah Burnham, "The Atlanta Federal Penitentiary and Area Jews: A Social Service Study," Southern Jewish History 21 (2018): 35–39.

[99] Tabak, Robert. "The Emergence of Jewish Health-Care Chaplaincy: The Professionalization of Spiritual Care"." American Jewish Archives Journal 62 (2010).

serving Jewish students on college campuses and while most college students do benefit from the spiritual care of a chaplain, Hillel rabbis wore many hats for their Jewish constituents. While this development presaged the development of the "community rabbi", their target audience was not health care. Jewish patients in hospitals would have been spiritually tended to by a congregational rabbi, if they were in a Jewish hospital, or potentially a Christian chaplain, if they were not being treated in a Jewish hospital.

After WWII, parallel to the expansion of Jewish chaplains serving throughout the military, the demand for Jewish chaplains grew louder across civilian sectors. This expanded demand drove the need for a more standardized training program. In 1948, a Jewish healthcare chaplain training curriculum was created at Mt. Sinai Hospital, in New York City. Many other Jewish organizations and hospitals across the US followed suit. An early participant in the Jewish chaplaincy training, Rabbi Israel J. Gerber, enthusiastically wrote of his Jewish chaplaincy training in Boston, "I am so impressed with their value that I have decided to write out my experiences so that they may stir other rabbis to undergo similar post-graduate training."[100] Gerber was not the only individual to see value in the role of chaplain. By 1950, there were almost 500 full time chaplains employed full-time outside of the military.[101] Until Gerber's CPE training for rabbis, CPE was almost exclusively Christian in nature. A Jewish CPE program could use Jewish values and texts in preparing chaplains to serve.

Even as chaplain training programs were expanding, various Christian denominations moved ahead on the organizational front, organizing professionally on a national scale. In

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[100] Tabak, Robert. "The Emergence of Jewish Health-Care Chaplaincy: The Professionalization of Spiritual Care"." American Jewish Archives Journal 62 (2010).

[101] Tabak, Robert. "Jewish Chaplaincy into the 21st Century." Journal of Jewish Communal Service 74, no. Fall 1997 (1997).

1945, the Institute for Pastoral Care was founded in Boston. The following year, the Chaplains Section of the American Protestant Hospital Association was founded, and went through a number of iterations, becoming the College of Chaplains in 1968. The Lutheran Advisory Council was formed in the late 1940's. In 1957, the Southern Baptist Association of Clinical Pastoral Education was formed, to train Southern Baptist chaplains. The National Association of Catholic Chaplains was founded in 1967. Finally, in 1967, the Association for Clinical Pastoral Education (ACPE) was created, by a merger of the Institute for Pastoral Care, the Council for Clinical Training of Theological Students, the Lutheran, and Southern Baptist groups.[102] There was no Jewish representation at that time, and no representatives from other faiths, in those early days.

As the numbers of Jewish chaplains grew, so did the need for Jewish CPE educators, who could utilize Jewish values and language in teaching pastoral care. In 1958, Rabbi Fred Hollander was approved to be a CPE supervisor by the board of what became the Association for Clinical Pastoral Education (ACPE). He was "almost certainly" the first Jew to gain this certification. He began running his own training programs in the summers, which attracted many ordained rabbis and rabbinic seminary students, looking to widen their skills.[103]

Even with this growth and demand for services by Jewish chaplains, the idea being a full-time Jewish chaplain was not considered a viable path, for rabbis. The prevailing stereotype of a rabbi was that they were to serve the Jewish people in the shape of congregation, from the bima of a synagogue. A glimmering awareness of change was on the horizon, however. In 1977, an HUC-JIR recruiting publication noted the existence of non-

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[102] https://ACPE.edu

[103] Tabak, Robert. "The Emergence of Jewish Health-Care Chaplaincy: The Professionalization of Spiritual Care"." American Jewish Archives Journal 62 (2010).

congregational chaplaincy careers, offering profiles of college Hillel rabbis and rabbis serving in correctional institutions.

The desire to serve the Jewish people as a chaplain continued to grow, the numbers of chaplains continued to increase, despite the dearth of formalized, Jewish training and a specific Jewish certification process, and a social stereotype that if one is a rabbi, they serve in a congregation. However, there was still no national organization for Jewish chaplains to network and share knowledge, experiences, and best practices. It was not until 1990, that the National Association of Jewish Chaplains (NAJC) was founded, thirty years after Christian denominations had organized.[104] NAJC chose to use the title of Chaplain, rather than Rabbi, partially in acknowledgement of the long history of that title as serving religious and spiritual needs in the military. Another motivation for the choice of title was to avoid a stalemate within the Jewish religious denominations. Liberal Jewish seminaries were ordaining women. The groups within Judaism practicing Orthodoxy did not recognize women as rabbis.[105] In 2014, the NAJC renamed itself as "*Neshama*: Association of Jewish Chaplains, with the mission of "providing ongoing education, training, certification, and sacred community. NAJC advocates for Jewish chaplains and chaplaincy."[106]

While the chaplain population was overwhelmingly male in the mid-late twentieth century, there were social changes coming in that arena, as well. Contributing to that evolution is that, before 1972, all American Reform rabbis were male. It was not until after the first female rabbi, Rabbi Sally Priesand, was ordained in 1972 that women could take up the rabbinic mantle in service to the Jewish people. It did not take long before women rabbis

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[104] Wendy Cadge, Bethamie Horowitz. "Mapping Jewish Chaplaincy." Chaplaincy Innovation Lab, 2022. Page11
[105] Wendy Cadge, Bethamie Horowitz. "Mapping Jewish Chaplaincy." Chaplaincy Innovation Lab, 2022. Page 63.
[106] www.najc.org

entered chaplaincy, in every field where chaplains could serve. In the 1985, HUC-JIR Rabbinic student, Julie Schwartz elected to enter the Navy as a candidate for active-duty Naval Chaplain. This presented a challenge to the Jewish Welfare Board (JWB), the accrediting body in which Orthodox, Conservative and Reform worked together to endorse Jewish military chaplains. Orthodox members of the JWB could not approve endorsing a female rabbi. That situation is a topic for a different thesis. Suffice it to write here that Rabbi Julie Schwartz was eventually endorsed by the JWB and became the first active-duty female chaplain to serve the US Military, in the Navy.[107] There are now approximately 1,000 Jewish chaplains serving across many capacities in the US.[108]

Jewish chaplains: Research and Reflections from the Trenches of Contemporary Healthcare

Let us turn our focus to contemporary times and read the voices in the field, both data-driven and anecdotal. This concluding section of chapter five will share voices from the field of contemporary Jewish chaplains as well as the results of recently released studies on the field of chaplaincy.

The Center for Chaplaincy Innovation conducted a survey from March 2-23, 2022. The report “Survey of Demand for Chaplaincy among U.S. Adults,” was created from the responses of 1,096 adults. The results revealed that approximately 25% of the American population has had an interaction with a chaplain in the past five years. This survey includes numbers from the Covid Pandemic, which adds a layer of complexity. Many hospitals restricted visitation during the first year of the pandemic. The survey also asked about where

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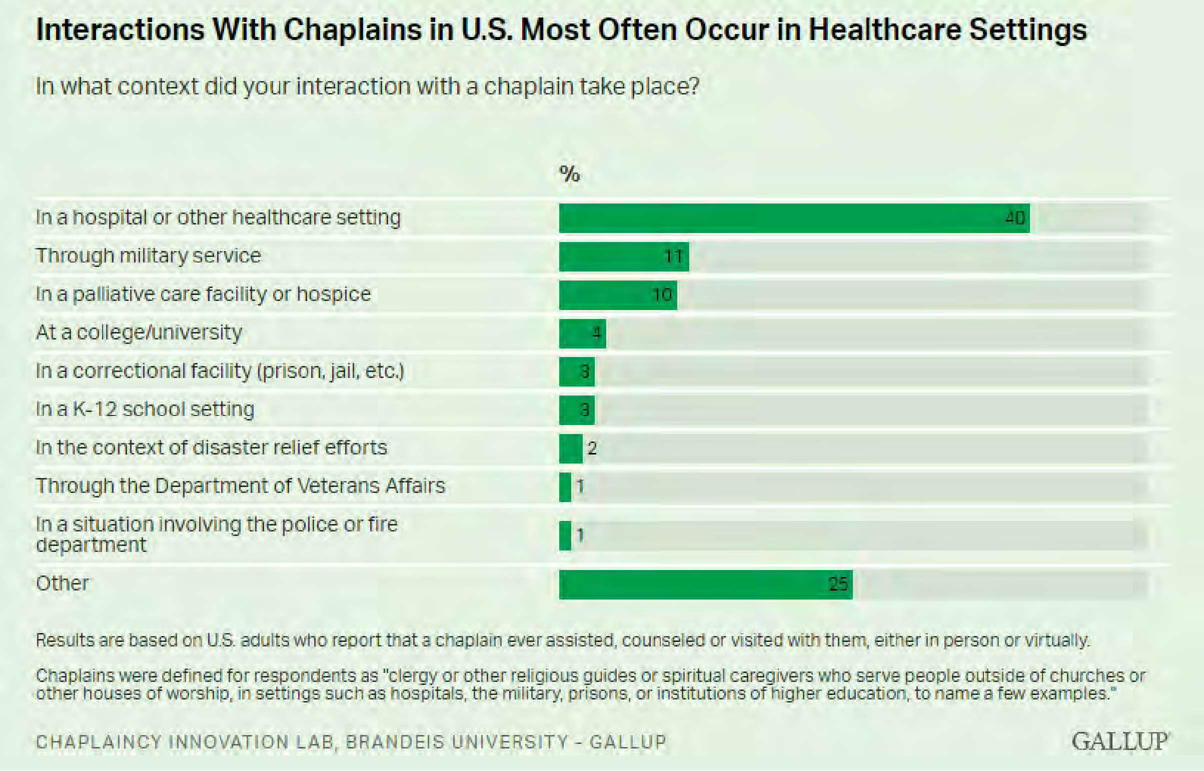
[107] Slomovitz, Abraham Isaac. *The Fighting Rabbis.* New York, NY: New York University Press, 1999. P 126

[108] Wendy Cadge, Bethamie Horowitz. "Mapping Jewish Chaplaincy." Chaplaincy Innovation Lab, 2022.

the chaplain interaction took place. The table below, also from the report, shows that break out. As the reader can see, 50% of the interactions took place in a healthcare setting, a hospital or hospice agency. Had more families been able to be with their family member in the hospital, there is a question about how the numbers may have been different.



Interactions With Chaplains in U.S. Most Often Occur in Healthcare Settings

In what context did your interaction with a chaplain take place?

Results are based on U.S. adults who report that a chaplain ever assisted, counseled or visited with them, either in person or virtually.

Chaplains were defined for respondents as "clergy or other religious guides or spiritual caregivers who serve people outside of churches or other houses of worship, in settings such as hospitals, the military, prisons, or institutions of higher education, to name a few examples."

CHAPLAINCY INNOVATION LAB, BRANDEIS UNIVERSITY - GALLUP

[109]

A follow up question asked if the respondent had found the interaction valuable, 55% of the individuals answered “very” and 31% answering “moderately” valuable. The poll also reveals that spiritual support is far more then prayer. The topics of conversation range from health, dealing with loss, relationships and more. The chart, below the answers to the poll.

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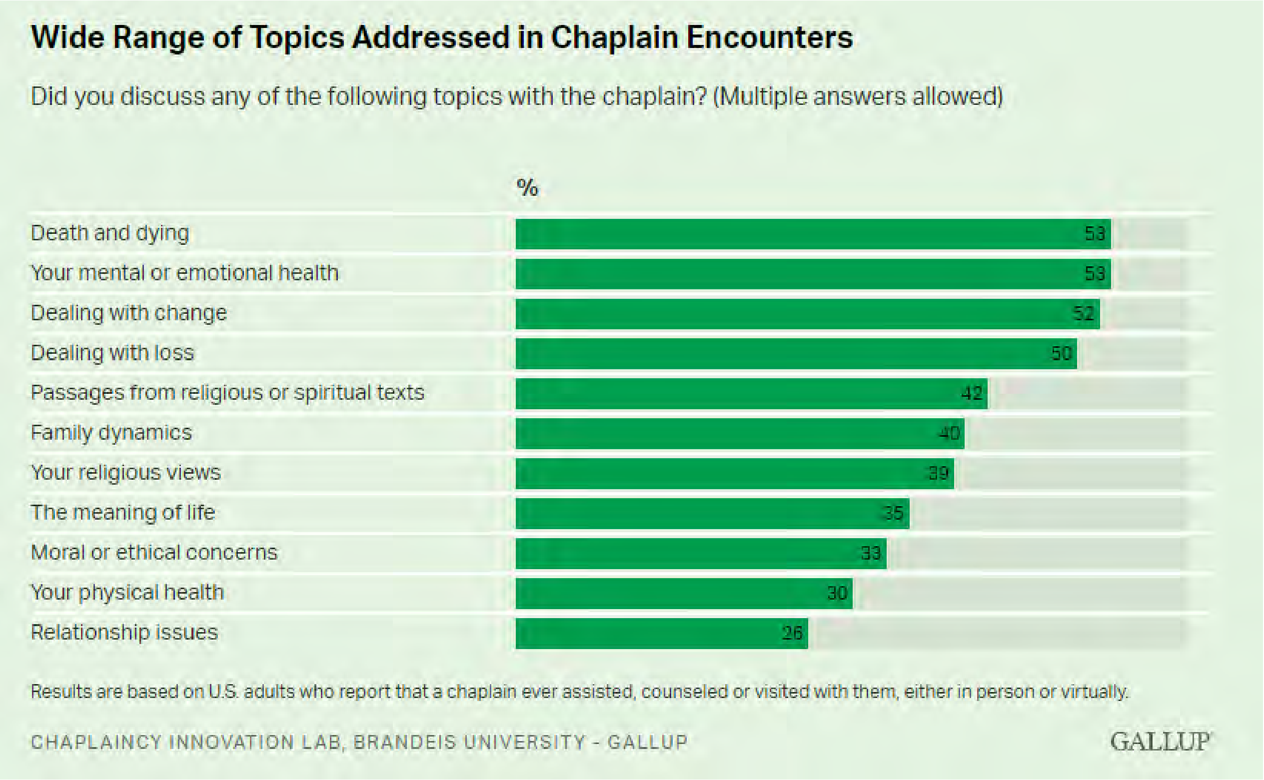
[109] Saad, Lydia. "One in Four Chaplains Have Been Served by Chaplains." In Gallup Blog: Gallup, 2022.



[110]

Given the declining number of Americans who are affiliated with a Church or Synagogue, these numbers, and the locations of the interaction are unsurprising. Many individuals no longer have a relationship with a pastor, priest, or rabbi. This leaves them with less support, when challenging life events occur. If we add to this the disruption of the Covid pandemic and the number of Americans who were hospitalized or died during the first two years of the pandemic, these numbers might even be higher, if there were more chaplains available to serve in accessible locations. There is a pipeline of Jewish chaplains, and the numbers are slowly increasing. Nearly of quarter of the theological schools in the US have started degree programs for chaplains in the past 20 years, and the numbers of individuals completing CPE training is increasing. At this time, 9 of the 11 (81%) American Jewish

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[110] Saad, Lydia. "One in Four Chaplains Have Been Served by Chaplains." In Gallup Blog: Gallup, 2022.

seminaries require or encourage their students to take CPE classes. The table below lists the Jewish seminaries in the US and the chaplaincy preparation requirement for their students:

Institution	One 400-hr. unit CPE requirement	Has a separate Track for Chaplains
Academy of Jewish Religion (NY)	Required for those pursuing chaplaincy	Yes, within rabbinical school
Academy of Jewish Religion California	Required for all rabbinical students	Yes. There is a separate chaplaincy program, with CPE requirements, for individuals who aren't ordained
Aleph: Alliance for Jewish Renewal	Required for all rabbinical students	Yes. There is a separate program for Rabbinic Pastor, where CPE is requeired for those who don't already have it.
American Jewish University (Ziegler School)	Not ascertainable through the website.	Unknown
Hebrew College	Encouraged for all students	Yes
HUC-JIR	Rabbinical students are required to complete a pastoral care internship; most complete a full unit of CPE to meet this requirement	Yes
JTS	Required of all rabbinical and cantorial students	Yes
RRC	Required of all rabbinical students	yes
YU- RIETS	No	Yes, there is a specialization in pastoral counseling, with an Advanced Certificate in Pastoral Counseling
Yeshivat Chovevei Torah	Required	Yes
Yeshivat Maharat	Encouraged	Unknown

Chaplaincy Preparation Requirements in American Rabbinical Seminaries[111]

As the field of Pastoral Care and chaplaincy has become professionalized, the academic institutions training Jewish leadership sees the value, both to students and their future

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[111] Wendy Cadge, Bethamie Horowitz. "Mapping Jewish Chaplaincy." Chaplaincy Innovation Lab, 2022. P.45

constituencies. Seminary support in this activity is fundamental, as it also encourages students to develop increased self-knowledge and pastoral presence provided by CPE.

Why chaplaincy and what is the Jewish connection?

For this thesis, I interviewed Jewish individuals serving as chaplains. Each were drawn to the role of a chaplain for a variety of reasons. While this is an admittedly a very narrow selection of the chaplains in the US, their backgrounds were varied, as was their path to the chaplaincy. The older stereotype that chaplains are people who "can't cut it in congregations" is increasingly recognized as invalid.[112] As you will read, some of the individuals went directly from ordination into a Chaplain role, others went into pulpit service initially, and not all Jewish chaplains have the title "rabbi". This portion of the chapter will review what drew these individuals to the chaplaincy, their thoughts on how their role connects to Judaism, as well as changes they have witnessed.

Rabbi Edie Meyerson serves in New York City, as the Associate Professor, Geriatrics and Palliative Medicine, Mount Sinai, and Director of Pastoral Counseling and Bereavement Services at the Hertzberg Palliative Care Institute at Mt Sinai Hospital. She knew chaplaincy was the rabbinate she would build, during her first unit of CPE. The one-on-one aspect of working with patients and helping them determine their values and choices was fulfilling to Rabbi Meyerson. She says that "Judaism chooses life. In the palliative care setting, I work with patients to define their life on their terms." She has found "with

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[112] Silberman, Rabbi Jeffrey. "The National Association of Jewish Chaplains." The Journal of Pastoral Care 46, no. 1 (1992). Editorial in which Rabbi Silberman notes that stereotype, as NAJC is founded.

chaplaincy I can see that there are so many ways to be Jewish, and be in the world. As a chaplain I help people find their own way."[113]

In her fifteen-year tenure at Mt. Sinai, Rabbi Meyerson has seen increased awareness and cooperation between the medical care and spiritual care teams. She has also been able to influence that development in her role as faculty. She works with the residents during their Geriatric rotation, helping them process their experiences. She encourages the residents to understand that the beliefs which support them currently may not be the beliefs that will do that in the future, and that patients will go through a similar evolution. Rabbi Meyerson has witnessed the "professionalization" of the chaplain role as well, with individuals shifting from "just clergy" to deeper levels of CPE training and awareness during her years of service. The third item noted by Rabbi Meyerson is the change in funding for chaplains. Her role was originally funded by a philanthropic grant. The department quickly saw the value of her role, not just to patients but to staff and residents. They funded her position directly and have since have expanded the chaplains' reach by embedding dedicated chaplains across the units, including heart failure, solid tumor oncology and three ICU teams.

Rabbi Eric Weiss is the recently retired President and CEO of the Bay Area Jewish Healing Center (BAJHC), San Francisco. Like Rabbi Meyerson, he also intended for his rabbinate to be one of pastoral and spiritual care outside of the synagogue. He was ordained in 1989, joining the Bay Area Jewish Healing Center (BAJC) which provided pastoral services for the community of an estimated 75% of Jews in the San Francisco Bay area who were unaffiliated with a synagogue. He remained with BAJHC until the center closed in the summer of 2022. Rabbi Weiss felt called to chaplaincy and its connection to the Jewish

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[113] Rabbi Edith Meyerson, Ph.D. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (August 23, 2022).

values of valuing life and respect due each human. He felt that pastoral care was about nurturing a community, based on the ways people cared for one another and views tangible caring as one of the sociological markers of any community.[114]

Rabbi Weiss' views on change took a more holistic view of the future. He recognized the philanthropic foundations of chaplaincy, like Rabbi Meyerson. The BAJHC itself was largely funded through grants. One of his longer-term goals for chaplaincy was greater integration and parity with the medical team. In his view, the philanthropic and "chaplain as overhead" funding needs to change. Rabbi Weiss felt one of best paths to accomplish that goal would be for palliative care and spiritual care to become billable activities in a hospital setting. As the chaplaincy becomes more professionalized, hospitals were doing patients a disservice by not utilizing chaplains with pastoral care training. This will be revisited in the final chapter.

Rabbi Susan Moss serves as a palliative care chaplain on the Saint Raphael Campus at Yale in New Haven, Connecticut. She noted that she had a part of her which was always drawn to chaplaincy. She was "eager for to begin" her first unit of CPE. Moss found the opportunities for interpersonal connections and supporting a person through difficult times to be compelling. She elected to serve as a congregational rabbi for three years after ordination in 2015. She was aware of the pull of pastoral care, remarking that she was the rabbi on the clergy team who took on the majority of pastoral responsibilities. After her first contract she began a CPE residency and has served as a chaplain in various healthcare and educational settings since that time.[115]

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[114] Weiss, Rabbi Eric. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (August 12, 2022).

[115] Moss, Rabbi Susan. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (August 8, 2022).

Rabbi Moss' chaplaincy service to date has mirrored some of the changes of chaplaincy writ large. After her CPE residency, she worked with both with ambulatory and in-patient settings, her time divided between the two. Shortly after those experiences, she was tasked with setting up an outpatient clinic for oncology patients, along with a social worker, nurse and doctor, working together. The team experimented with different models of coordination, developing a system with the chaplain and physician making calls together for simultaneous assessments. Currently Rabbi Moss is on a dedicated palliative care team. Because the role integration, she finds the experience of palliative care chaplaincy gives her a better "big picture" awareness of the holistic view of the patient, which allows her to better serve the patient and communicate patient values, to the care team.

Chaplain Miriam Karp is a board-certified chaplain and Orthodox Jewish woman who began her chaplaincy in hospital settings. Currently Chaplain Karp services as a community chaplain with K'vod Connect, an agency managed by the Jewish Family Services of Cincinnati, OH, and largely funded by grants from the Jewish Foundation. The clients of K'vod Connect are usually unaffiliated Jews and somewhat isolated, socially. Her constituency tends to be older, or more chronically homebound. Chaplain Karp focuses on a patient's *neshama*, their soul or spark of God. Within those moments, she sees a wider connection to all Israel. "I'm amazed at how therapeutic it is for people, that I am just there to be with them, to care about their life story."[116]

Rabbi MD is a staff chaplain, serving with a southern hospice agency. They started their rabbinate as a congregational rabbi, and like Rabbi Moss, was drawn to the pastoral aspects of service. After being diagnosed with a chronic illness, Rabbi MD stepped away

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[116] Karp, Chaplain Miriam. "Perspectives on Jewish Palliative Care Chaplaincy." By Edith Yakutis (2022).

from the 24/7 demands of congregational life. Once their illness stabilized, they entered CPE training and are board-certified as a chaplain. For Rabbi MD, providing the "Jewish connection" to patients who may be unaffiliated with a synagogue, but find their Jewish identity to be very important is their primary motivator. I also noted in chapter three, Rabbi MD finds a textual connection with *Bava Metzia* 86b and Talmudic images of Rabbi Yochanan reaching out to his colleagues who have fallen ill, to support them and raise them up to healing. Rabbi MD sees a level of spiritual accompaniment in this text which applies to their role for patients in both hospice and memory care. They find moments of sacred space and connection, giving both Rabbi MD and the patient and family a solid measure of spiritual strength.[117]

Rabbi MD has seen an "explosion of assisted/older adult living communities and memory care units." The caseload of the hospice agency with which they work as seen caseloads rise and patients living to be much older than when they started. Rabbi MD has also recently experienced that their agency and others, considers spiritual care a best practice, moving dedicated chaplains to the forefront of each interdisciplinary team, being sure their voice and experience of the patient and their family is heard.

Cantor Lanie Katzew is the retired Director of Pastoral Care of Cedar Village in Cincinnati, Ohio. CPE was not an offering at HUC-JIR when she was in seminary. She came to chaplaincy later in her career, after twenty years serving as a congregational cantor, and work with the Union for Reform Judaism (URJ). After her personal experiences in caretaking for family members, Cantor Katzew acknowledged her strong pastoral care skills. She completed her CPE units while serving at Cedar Village. One of her touchstones in

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[117] MD, Rabbi. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (September 9, 2022).

chaplaincy is the concept of *tzimtzum,* which is the concept that God began the process of creation by *tzimtzum,* or withdrawing God's self from an area, to allow space for creation to begin. Through *tzimtzum,* the chaplain can create a space for the patient and their family, to be and to come to their own knowledge and decisions about how they want to live their best life. We will read more of Cantor Katzew's views on future changes, in the final chapter of this thesis.[118]

Rabbi BN is currently serving in North Carolina as a "per diem" (a scheduled but not full-time position) for a large medical center. At HUC-JIR, they found the CPE course to be one of the most meaningful events of their education. After ordination, they began working as a congregational educator. They found the call of chaplaincy to be far stronger, and transitioned into that role, and has served as a healthcare chaplain since 2016. Rabbi BN has served primarily in the South outside of major metropolitan areas. Even though they are very much in the religious minority, they find the Jewish concept of accompaniment and respect of the sick to be deeply meaningful, as they serve patients and their families. In the larger teaching hospital where Rabbi BN serves, he is seeing increasing focus on tracking chaplains' time, to effect change. Recently, the team has been using comparative studies with similar sized institutions in other markets, to justify requesting increases in chaplain headcount. The Spiritual Care staff also has periodic "Medicare stats" tracking, where the chaplains track their time in 5-minute increments per unit, again as evidence of the need for increased headcount.[119]

Rabbi Leslie Bergson knew, during seminary, that she would become a chaplain,

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[118] Katzew, Cantor Alane. "Perspectives on Jewish Palliative Care Chaplaincy." By Edith Yakutis (June 27, 2022).

[119] BN, Rabbi. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (September 9, 2022).

while in the class, “Rabbi in the Hospital.” After being ordained in 1995, she spent the early part of her career as a Hillel director and chaplain. After the 2008 stock market crash, she determined to make a full career transition to the “real role” she wanted. She became board certified and spent a number of years as a hospice chaplain, with hospice agencies. She greatly treasured the ability to both interact with patients and families and great need and have a reasonable workload.[120]

The biggest change Rabbi Bergson encountered was the general tightening of Medicare rules regarding enforcement of the six-month terminal diagnosis. While Medicare does allow patients to receive hospice care after the six months, there is now an onerous certification process. She has seen a lot more time invested in validating that the patient, which causes the families of patients a great deal of stress.

As we have read in this chapter, the field of Jewish chaplaincy continues to grow and professionalize with no single point of entry into the role. Metrics and data-based research is beginning to support the value which spiritual care provides patients. During the interviews, each individual noted how spiritually fulfilling their role was, even if non-chaplains did not deeply understand their job. They also described highs and lows of their role. More than a few of those interviewed marked how pleasant it was to not have to serve a congregational board of directors, as well the congregation.

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[120] Bergson, Rabbi Leslie. "Perspectives on Jewish Chaplaincy." By Edith E. Yakutis (September 14, 2022).

CHAPTER 6: CHRONIC ILLNESS AND THE ROLE OF THE JEWISH CHAPLAIN

We have reviewed the foundations for Jewish approaches to chronic illness, medical approaches to chronic illness and the development of chaplaincy in general and Jewish chaplaincy specifically. What are the next steps for Jewish chaplaincy as increasing numbers of people live longer lives, often with chronic illness? How can spiritual care be provided?

Long term, systemic change is needed to improve access to palliative care chaplaincy, as well as public and medical school education. There is also shorter term, tactical change which could be implemented, including community chaplaincy and telechaplaincy. This chapter will outline these recommendations for the future of palliative care chaplains.

Long Term Change for Spiritual Care

Studies repeatedly show the need for discussions of spirituality in healthcare, and especially when patients are confronting chronic, life-limiting illness. The New England Journal of medicine outlined just one aspect of patient-centered spiritual conversation in 2015. The emphasis added is mine:

> “Data suggest that spiritual concerns are common in persons with serious illness and that the majority want to discuss their spirituality with their physicians. Nevertheless, less than 50% of physicians believe that it is their role to address such concerns, and only a minority of patients report having their spiritual needs addressed. Widespread consensus holds that health care chaplains should provide spiritual care yet there are **insufficient numbers of health care chaplains** and **very few are certified in**

> **palliative care.** Thus, most seriously ill patients depend on other members of the health care team to address spiritual concerns”[121]

There are insufficient numbers of chaplains and specifically, palliative care chaplains. Patient needs are going unmet. A contributing factor to the shortage of chaplains is that they are currently considered overhead, on a hospital budget. Chaplains are not viewed as core enough to the mission of curative care. Additionally, chaplains are not a reimbursable expense through insurance and hospitals. My first recommendation is a cautious endorsement that this billing status must change if we are to drive increased chaplain population and better meet the needs of chronically ill patients.

There is precedent for this change in hospital or palliative care billing practice, however. It is mandated that hospice service provide the services of a certified chaplain whose time is tracked and billed. In most hospital budgets, however, chaplains are listed the “overhead expense” budget line. Without a billing code, chaplains are considered overhead. Healthcare service providers chronically underfund the role of a professional chaplain, or utilize volunteers, who may not be trained in CPE, in order to save on expenses. If the role of chaplain were billable, with certification requirements, and quality measures, the same way in which physicians are billed, there would be a clearer road to parity. There is a great deal of research that needs to be done on this topic, but it has begun. As this thesis was being researched, the Centers for Medicaid & Medicare services approved billing codes for chaplains, specifically for chaplain time spent in assessment, group and individual

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[121] Amy S. Kelley, M.D., M.S.H.S., and R. Sean Morrison, M.D. "Palliative Care for the Seriously Ill." New England Journal of Medicine 373 (2015).

counselling. Healthcare Common Procedure Coding System (HCPCS) coding for chaplain services went into effect October 1, 2022.[122]

This is a new step and somewhat controversial. While the National Hospice and Palliative Care Organization (NHPCO) advocated for this change, writing that the codes,

> "…will provide the mechanism for gathering data on chaplain visits and open the door for inclusion of chaplains in quality measures such as NQF 3645. Through this measure and other measures, the Chaplain services will improve the quality of **whole person care that every beneficiary deserves**."[123]

Several insurance companies also advocated for these coding changes, noting that the supplemental benefits would lead to increased demand for the service.

The controversy about chaplain billing stems from concerns about mechanization of spiritual care delivery. The chaplains I interviewed had mixed opinions on the topic of billing codes for chaplaincy and Spiritual Care programs. Rabbi Eric Weiss gave a resounding YES, that chaplains should be billable, if they are ever to achieve an equal seat at the healthcare table. Others were less emphatic, citing concerns over mechanizing what should be a spiritual relationship, and the risks of incentivizing "tick box" behaviors which don't connect with patients. Rabbis BN and MD took a middle path, with activities such as chaplain-led Spiritual Life Reviews being billable, but other spiritual interventions not so, as "billable activities are very process-oriented. That can fence us in to not really allowing the time and patience needed to provide true spiritual care."[124] My first recommendation is that there be continued advocacy and research, resulting in categories of billable chaplain activities.

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[122] Services, Centers for Medicare & Medicaid. "(HCPCS) Level II Final Coding, Benefit Category and Payment Determinations." 2022.

[123] NCPCO. "Coding for Chaplains Approved!" news release, 2022.

[124] MD, Rabbi. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (September 9, 2022).

My second recommendation to provide Jewish Chaplaincy is more ambitious. I support adding a palliative care benefit to Medicare, similar to the current hospice benefit. This would improve availability of palliative and spiritual care for patients with chronic illnesses. Replacing the current patchwork system of billing for palliative care with a single unit of care and assurance of payment would incentivize physicians to recommend and provide palliative care. With that incentive, regulatory guidance would mandate spiritual care, again similar to the hospice benefit, with palliative care accreditation requirements and standards. Medicare would pay more to health care providers achieving those standards.

My third recommendation is to increase public education, to educate on the differences between palliative care, and hospice. There is consistent confusion of the terms, and underlying fear that receiving palliative care or "going into hospice" is giving up on life. Rabbi Edie Meyerson refuted that statement categorically, stating that palliative care "allows people to define life on their terms and choose how they want to live it."[125] She also noted, proudly that "Reform Judaism connects with palliative care, because both are ALL about informed decision making."[126] American culture has largely avoided discussion about the natural outcome to birth. Yet, as Rabbi Eric Weiss stated, "Becoming sick, coming to one's last breath, and folding grief into one's life are three of the universal human life experiences."[127] Perhaps as more of American society ages, there will be a normalization and more public conversation around how to live and prepare, spiritually, for the inevitable end of life.

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[125] Rabbi Edith Meyerson, Ph.D. "Perspectives on Jewish Chaplaincy training in communication skills, and no education regarding the types of." By Edith Yakutis (August 23, 2022).

[126] Rabbi Edith Meyerson, Ph.D. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (August 23, 2022).

[127] Weiss, Rabbi Eric. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (August 12, 2022).

I suggest another category of education, as well. Education for the medical field should also include training about spiritual care and the role of certified chaplains in providing complete care for the patient. In 2021, R. Sean Morrison, MD, a geriatric and palliative medicine physician, and professor and chair of the Department of Geriatrics and Palliative Medicine at the Mount Sinai Health System in New York, wrote an article with Mireille Jacobson, who serves as co-director of the Aging and Cognition Program at the USC Schaeffer Center for Health Policy and Economics in Los Angeles and an associate professor at the USC Davis School of Gerontology. Their article is titled, "Palliative Care Works, So Why Is It Rarely Used? Follow the Money." The authors decry the lack of medical school education on spiritual care options for patients, saying,

> "Generations of physicians have been trained to expertly diagnose and treat disease but don't have the skills to treat the physical, emotional, and spiritual suffering that accompanies serious illness. Across 10 years of medical education, one of us (RSM) received one 30-minute lecture on pain medications, no non-hospital and physician services available to patients and families and whether such services are covered by Medicare and other insurance programs."[128]

The authors also recommended adding questions about palliative and spiritual care to board exams, as well as required continuing education about palliative care for hospital licensing and accreditation. During our interview, Rabbi Susan Moss talked about the impact of a change to medical training at Yale. She observed groups of residents, nursing students, chaplain trainees and social work students training together with the goal of gaining a better understanding of each group's areas of expertise.[129] She believed it showed great promise for

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[128] R. Sean Morrison M.D, Mireille Jacobson "Palliative Care Works, So Why Is It Rarely Used? Follow the Money." STAT (2021). https://www.statnews.com/2021/03/23/palliative-care-works-so-why-is-it-rarely-used-follow-the-money/.

[129] Moss, Rabbi Susan. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (August 8, 2022).

future understanding and cooperation, on any future interdisciplinary teams on which those students served. Again, awareness and knowledge of the benefits of spiritual care would reduce the reticence to engage palliative care teams and chaplains.

The practice of an embedded chaplain in healthcare units (palliative and otherwise) is my fourth recommendation to address spiritual care of the chronically ill. At Mt Sinai, where Rabbi Edie Meyerson serves, embedded chaplains in each unit are their gold standard. Perhaps with changes in medical training and students working together as an interdisciplinary team, as I recommended earlier, the practice of medicine will evolve, viewing the patient more holistically and not as a collection of medical problems.

I also recommend driving awareness within the chaplain culture itself, of the palliative care certifications that exist. Publicizing additional continuing education and available certification for the specialty has the potential to expand the availability of knowledgeable chaplains. To incentivize the additional certification, chaplains with that endorsement could be paid a higher rate. Incentivizing the certification would drive additional well-trained chaplain resources for patients and teams.

Near Term Changes to improve access to Spiritual Care

When making change in the corporate world, there is often an unspoken goal of providing some “quick wins,” and change that yields immediate, visible progress. My first recommendation in the “quick win” category is to increase the numbers of chaplains to Jewish communities, reversing decades’ long decline. In the report, “Mapping Jewish Chaplaincy”, it was noted that in 2022, twenty-five communities have at least one Jewish, community-based chaplain. That number is a decline from the forty-eight communities which supported community chaplains in 1950.[130] Given the documented decline in synagogue membership, how else the Jewish community to be aware of and provide community to their brethren? The reduction in numbers was unexpected, to me. Community chaplains provide connections for individuals who may no longer drive, and may be working to "age in place." Those two goals can result in increased social isolation, which the community chaplain can help remedy. This dearth of spiritual outreach represents a problem in reaching older, potentially isolated individuals, or those with chronic illness.

Per the report, community chaplaincy is predominantly run and funded under the auspices of Jewish Family Services(JFS). The chaplain can refer clients for assistance with food, travel and other services including healthcare. This is the case with K'vod Connect in Cincinnati, where Chaplain Miriam Karp has relationships with isolated individuals. She sees the needs of her clients. She works to provide clients with connections to services and a wider community to provide ongoing support.[131]

Another shorter-term solution for the chronically ill to receive spiritual care would be to establish telechaplaincy outreach for established patients. Telehealth, the practice of delivering healthcare were patient and providers are separated by distance, but connected by information and communication technology had begun to be cautiously tested by the 2010's. Usage, however, increased greatly during the Covid pandemic, as telehealth obviated the need for patients to visit doctor's offices and potentially risk exposing themselves or others to a contagious illness. This rise of telehealth is particularly noticeable in the area of behavioral health services, where adoption usage after January 2020 "stabilized at a 70% increase

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[130] Wendy Cadge, Bethamie Horowitz. "Mapping Jewish Chaplaincy." Chaplaincy Innovation Lab, 2022.
[131] Karp, Chaplain Miriam. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (June 10, 2022).

compared with pre-pandemic levels."[132] This development could be promising for the delivery of spiritual care. Rabbi Susan Moss offers telechaplaincy as a way to connect to the individuals she serves, noting it truly allows her to "meet people where they are."[133] Awareness of telechaplaincy is growing. The Center to Advance Palliative Care (CAPC) has published guidance in having a successful telechaplaincy session, featuring Rabbi Edie Meyerson.[134]

Numerous chaplains interviewed agreed that "telechaplaincy is telehealth," and that they look forward to seeing the trend develop. A recently published study begins to explore the potential benefits and risks of telechaplaincy, as it gains wider use. The Veteran's Administration began piloting telechaplaincy in the 2010's. They found that it reduced travel time for veterans, and allowed chaplains to coordinate "TeleChaplain Family Reunions", often for "last goodbyes." Other healthcare systems were also studied in the report with general growth in demand seen. [135]

The study also outlines risks that come with telechaplaincy. While it does improve access to spiritual care for rural or disabled populations, it sets up other barriers for others. Individuals who are economically disadvantaged, lacking broadband internet access, not as technically literate, or in cognitive decline are less likely to be able to gain benefits associated with telechaplaincy. During the pandemic, the CDC endorsed telehealth and waived regulatory challenges to reimbursement, but there is no certainty if that waiver will remain in effect. There is also the unknown territory of having chaplains serve predominantly

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[132] Winiger, Fabian. "The Changing Face of Spiritual Care: Current Developments in Telechaplaincy." Journal of Health Care Chaplaincy 29, no. 1 (2023/01/02 2023): 114-31.

[133] Moss, Rabbi Susan. "Perspectives on Jewish Chaplaincy." By Edith Yakutis (August 8, 2022).

[134] CAPC YouTube channel - Fast Five: Tips for Using Telechaplaincy to Bring Comfort and Peace

[135] Winiger, Fabian. "The Changing Face of Spiritual Care: Current Developments in Telechaplaincy." Journal of Health Care Chaplaincy 29, no. 1 (2023/01/02 2023): 114-31.

online. Will the presence of a computer screen between the patient and chaplain reduce the spiritual connection? My recommendation on telechaplaincy is that barring an emergent situation where there are no other options, that initial encounters and meetings be in-person. established relationship between the chaplain and the patient, then they can determine how they will interact, going forward.

Conclusion

Jewish chaplaincy has emerged to reach beyond the bima and become its own, established rabbinate and offering. As technology and education develop, Jewish chaplaincy must continue to develop and grow alongside. My recommendations of changing how hospital and palliative care chaplaincy, along with a broad array of education to the public and medical professionals and embedding chaplains in medical specialty teams will improve the availability and use of spiritual care. In the short term, telechaplaincy and additional community chaplains would also encourage better outreach, and connections with isolated individuals. There is promise for improvement, with individuals and groups seeking to create additional pathways to professionalize the field of chaplaincy. Jewish chaplains must not lag behind in the testing and adoption of new methods of outreach.

I quoted Abraham Joshua Heschel at the beginning of this thesis, that the measure of a society is how it treats is aged, weak and infirm. It is my hope that we will continue to keep his words in the forefront of our minds. There is more work to be done, to protect the sick, the frail and the aged, and seek to provide the Jewish people with spiritual care and nurturing that they need, in facing chronic illness, loss and grief.

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