Education and the Costs Associated with Death

by

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#### ABSTRACT

Cancer has a financial impact worldwide. According to a study published by the American Cancer Society, "cancer accounts for 1.5% of global gross domestic product loss per year" (John & Ross, 2010). The legal and economic costs of death are not something normally addressed with patients prior to the occurrence of death. With an integrative approach, education may help reduce financial stressors for both the patient and family, while offering cost saving benefits to the facilities involved. Studies have shown that education pertaining to advanced care planning help to reduce hospital visits and the costs associated with the last six months of life. Integrating additional education in the form of legal and financial planning prior to death will benefit patients. This may benefit hospitals concurrently, by reducing hospital visits or length of stays, saving millions in Medicare costs to the hospital. Hospitals currently focus on the emotional, spiritual and intellectual needs of the patient post diagnosis of a terminal illness. Education related to funeral planning, preparing a will, and financial preparedness need to be included in the structured patient education offered at facilities. Individuals that have a higher socioeconomic status are typically more prepared for the costs associated with death. Offering financial education will allow more individuals experiencing the terminal diagnosis to prepare for their impending death.

#### DEDICATION

This thesis is dedicated in loving memory to my younger brother, James Simundson. You always supported my schooling, and unfortunately your untimely death became the basis of my research.

I would also like to dedicate this to my mom, Cheryl Simundson. You have always supported me and encouraged me to pursue my dreams. It may have taken a little longer than I had planned, but I finally completed my master's degree! I love you very much.

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#### CHAPTER 1

#### INTRODUCTION

A diagnosis of a terminal illness is not something anyone wants to hear. Hospitals do not currently offer education to patients concerning the legal or economic issues that may arise with death. One estimate suggests that 27% of adults have given little to no thought to their end of life (EOL) care, and while 35% have given some thought to the issue, the majority have neither documented nor discussed their preferences with others (Pew Research Center, 2013). This paper will look at costs and services, both anticipated and unanticipated, that are associated with death. It will address the need for well- rounded education (social, spiritual, intellectual which includes economic and end of life planning) to be provided prior to death for the patient and family. Education may not only help the patient reduce some of the financial burden that can be associated with death, but early education provided for those that are anticipating death may also have a positive financial impact on the hospitals providing these education services. If death preparation remains low, expenditures are likely to rise substantially given the size and diversity of the older adult population (Harper, 2014). Whether the costs associated with medical diagnostics and treatment at the end of life (EOL) is sustainable is a question that is becoming more frequently asked.

#### CHAPTER 2

#### GENERAL COST OF CANCER

The legal and economic costs of death are not something normally addressed with patients prior to the occurrence of death. With an integrative approach, education may help reduce financial stressors for the family, while offering cost saving benefits to the facilities involved.

Structured education pertaining to finance or legal issues is not currently offered as a patient service in hospitals around the United States. Many hospitals will provide patient handouts and informational sheets that offer websites for patients to utilize. Massachusetts General Hospital offers patients a checklist for after a death. See Appendix A. The University of California San Francisco also has a similar handout addressing some of the legal and financial issues that may be encountered post death. See Appendix B. These examples are meant as a guide to help families be more aware of the many legal issues they may encounter. These handouts are given to family members after the death of a patient, rather than prior to the patient's death. If these informational sheets are given to patients prior to death, there is still the issue of the lack of human guidance and the limited availability to explain or answer any questions that arise. As patients navigate through their disease process, it may be difficult for them to have the time, energy, or ability to understand these informational sites. Patients may not possess the knowledge, education, or resources to even access the offered education. "People with greater socioeconomic status have a higher rate of participation in activities such as writing wills and advance care planning than those with lower socioeconomic status. U.S. people who are from minority racial and ethnic groups are less likely to have engaged in death preparation" (Kelley et al., 2010). Providing in-person legal and financial education to all patients, regardless of socioeconomic status, along with addressing issues such as costs of palliative care versus treatment, legal documents such as a will, medical power of attorney, and financial representatives may help reduce unanticipated costs after their death.

This paper focuses on the costs associated with death, but with an emphasis on stage IV cancer diagnosis deemed irreversible which ultimately result in death. Costs associated with treatments offered for various diseases can be immensely different. The financial models and information presented do include other types of disease and illness, but the financial impact of cancer is overwhelming worldwide. Costs associated with cancer are not only related to treatment and medical visits. The American Institute for Cancer Research (AICR) reports that cancer accounts for 1.5% of the global gross domestic product (GDP) loss every year. In terms of 'years of healthy life' (also known as years of life lost (YLL)) cancer cost Americans 83 million years of lost productivity and wages by the year 2008 (AICR, 2017). A study published in Norway in 2014 looks at the YLL of multiple cancers. "The number of deaths alone does not reflect the complete burden put on the society, as some cancers harm younger people more than others. The number

of years of life lost therefore depends on the age at death and the number of deaths at each age and may resolve some of the mismatch of disease impact derived from death numbers alone. Years if life lost data may be more useful in resource allocation and design of prevention programs (Thun et al, 2010; Carter and Nguyen, 2012). Earlier reports have shown that 25–30% of YLL in western countries are due to cancers (Mariotti et al, 2003; Santric Milicevic et al, 2009; Gènova-Maleras et al, 2011), based on fixed reference ages and subsets of populations. The different cancer subtype contribution to cancer-caused YLL varies substantially, and comprehensive and updated data on a population level are warranted" (Brustugun, 2014). The number of years lost does not include patients' families or caregiver support when addressing issues such as wages lost due to the care or death of the patient. Along with healthy life years, the Agency for Healthcare Research and Quality (AHRQ) reports that cancer cost Americans alone \$88.7 billion in 2011 (Elkins, 2019). Patients often use treatments such as chemotherapy, radiation, and surgeries as life-prolonging procedures, even though it is understood that these treatments will not cure the disease at this stage. "Many patients with incurable metastatic cancer initiate chemotherapy with unrealistic expectations of its potential" (Bao et al., 2018). Offering education to these patients when it comes to cost of treatment and financial obligation is necessary for patients to make the most informed decisions concerning their health care. When looking at the cost of treatment or life prolonging chemotherapies, the United States continues to see a steady increase in prices. A 2015 National Bureau of Economic Research study found anticancer drug prices at launch increased by 10% ever year between 1995 and 2013, about an \$8,500 annual increase. That's after an adjustment for inflation and survival benefits" (Bao et al, 2018).

A study completed looking at out of pocket (OOP) costs focuses on the financial strain and issues that come with cancer treatments. There are multiple concerns associated with the substantial increase in OOP costs associated with chemotherapy use, along with the use of continued end of life (EOL) chemotherapy. "Financial toxicity, including financial burdens of cancer treatment in terms of OOP costs, depletion of assets, medical debt, bankruptcy, and related stress have received increasing attention from the National Cancer Institute" (Bao, et al., 2018). Researchers, Bao et al., found that OOP costs associated with initiation of chemotherapy in the older patient population further added to financial stress and anxiety by an increase of 50% in the last-month-of-life OOP costs. Bao continues to show that when chemotherapy is used close to death it was even greater than 50%. These financial burdens were experienced by patients that had medical coverage, such as private health insurance or Medicare. Providing patients with the education surrounding costs both prior to, and post death is important in helping them make the most informed decisions.

The complexity of costs associated with cancer has not gone unnoticed. New treatments and medications are assisting in prolonging life of terminally diagnosed patients anywhere from a few months to one year and beyond. The average costs

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of extending a person's life for one year is calculated by a study published in 2019 by Elkins. In 1995 insurers paid approximately 54,100 US dollars for life extending medical treatment. The cost for life extending treatments and procedures has now risen to over 207, 000 US dollars in 2013. Innovation in cancer drugs has led not only to ever increased survival rates, but also improved treatment options, such as the move from intravenous to oral delivery methods. The Commission has also made an important contribution in opening the debate about the complexity of health-care costs in cancer care. The pharmaceutical industry stands ready to show the value of new cancer drugs, and to help generate savings where possible" (Bergstrom, 2012).

#### CHAPTER 3

#### FINANCIAL PROGRAMS OFFERED TO PATIENTS

There are various financial assistance programs associated with helping patients through both anticipated and unanticipated costs that arise when dealing with terminal illness. These programs can be found as government funded programs such as Medicaid, Food Stamps, Housing Assistance and other civil society programs. There are also state and federal laws that protect an employee from losing their job and/or health insurance when taking medical leave for extended illness. These laws (FEMLA) can also protect an immediate family member that may be suddenly playing the role of caregiver. Another form of assistance can be found through local and national charities. These are often privately funded and can provide transportation, help with utilities or other bills, and various other services. Many cancer centers and facilities offer a social worker or palliative care teams that offer some assistance in navigating the financial burdens associated with immediate and upcoming care. This assistance does not specifically focus on any legal or financial planning concerning the patient's impending death, or the financial issues that may arise post death for family members. As previously mentioned in chapter 1, some hospitals provide handouts to families to serve as a guide when navigating the unknown costs after the death of a family member. Any financial assistance that may have been offered or received while the patient was alive, does not carry over to help the family with costs that are incurred with the dying process and other unanticipated costs.

#### **CHAPTER 4**

ANTICIPATED AND UNANTICIPATED COSTS ASSOCIATED WITH DEATH There are various costs following the death of a patient. This paper is not able to focus on all costs, but will look at one of the most common anticipated costs. The most widely known anticipated cost associated with death is a burial, cremation, or funeral/celebration of life. Regardless of religious beliefs or decisions surrounding what will happen to the body after death, some sort of financial obligation will be assessed to the family. According to the National Funeral Directors Association (NFDA) the national average cost of a funeral in 2017 was 6,260 US dollars for cremation (see Appendix C) and 8,755 US dollars for burial (see Appendix D). These costs are not regulated and can vary immensely from state to state. The United States Federal Trade Commission (FTC) developed the FTC Funeral Rule, which helps consumers understand what it required by law when it comes to funeral planning. The costs included in the NFDA's average of funeral costs include items that are not required by law. The FTC Funeral Rule clearly states, "no state or local law requires the use of a casket for cremation. A funeral home that offers cremations must tell you that alternative containers are available and must make them available. They might be made of unfinished wood, pressed wood, fiberboard, or cardboard" (FTC, 2020). The uncertainty of laws and costs associated with funerals means that surviving family members may pay much more out of pocket than necessary. Funeral planning can be a very overwhelming and stressful situation for the family members. Costs can quickly get out of hand for the family and grief may cloud financial decisions that are made at the time. Offering education related to funeral planning and what is required by the state/local laws is another way to help reduce cost to the patient and/or family after death occurs.

Along with anticipated costs there are also unanticipated costs associated with the death. There may be legal fees, probate, death certificate copies, death announcement in the paper for debt collection, and many others. Many of these costs could be anticipated if there was education provided through a facility. Once a person has died, the question often lies in who is responsible for the debt that the family member has accrued during his/her lifetime. This can be a difficult area to navigate, because laws can vary greatly between states. An individual that is married and shares joint bank accounts, loans, or other bills in both of their names will be responsible for those bills. Bills that are solely in the deceased individual's name may be different. Another issue is responsibility of medical costs and bills after the death of the patient. After death who is responsible for the often-expensive medical bills that will follow? These are all questions that can be addressed prior to the impending death of the patient with appropriately educated staff.

Another unanticipated cost is lost productivity due to illness and ultimately death. These costs can be associated with both the patient and also family members that often act as caregivers. Lost productivity can be estimated by what Brown and Yabroff describe as the human capital approach. This approach uses gender and age specific average earnings along with estimated productivity trends to compute lifetime earnings by age. The loss of estimated earnings can be compared to an investment today to make up for the productivity accumulation throughout the patient's lifetime. The loss of wages due to missed work for the family members can also be estimated in productivity losses due to absenteeism. Using the human capital approach model, cancer costs are not just directly related to immediate costs. Financial education and planning would help reduce stress and worry which may lead to a speedier return to the workforce for family members affected by the patient's death. It is not the hospital's or care center's job to become financial advisors to every patient, offering a basic integrative approach to finance management from a legal perspective would still be beneficial for all. If programs were implemented addressing payments and write-offs for the hospital, it may work at increasing revenue along with a better projection for the upcoming fiscal year.

Hospitals have also seen a decrease in emergency room visits, hospitalizations and decreased hospital stays when patients are offered a more integrative approach to palliative care. A study performed by Richard Brumley, MD and colleagues focused on palliative care provided by one advisor versus an interdisciplinary team that focused on multiple areas of patient education. Brumley et al. report, "recent studies have found that, although costs of care vary from state to state and from hospital to hospital, they remain high in the last 2 years of life. In addition, previous studies focusing on costs of care in the last year of life found that average per-member costs have remained constant over the past decade, representing approximately 25% of all Medicare expenditures" (Brumley et al., 2007). As stated earlier, introduction of integrative education prior to death may help lower costs for hospitals as well as patients. In a study analyzing Medicare spending per beneficiary (MSPB) performed by Bowers et al. in 2018 it is explained how reducing Medicare spending can save hospitals money. Medicare adjusts payments made to the hospitals that are not directly associated to care. Bowers et al. explain how Medicare can profit or lose money based on length of hospital stays and uncovered costs associated with them. "MSPB measure is the ratio of the hospital's payment-standardized risk-adjusted MSPB amount to the episodeweighted median cost across all hospitals. The actual cost is the adjusted amount and the expected cost is how much the hospital believes the episode will cost based off of the weighted median across all hospitals. It is desired that the adjusted amount is lower than the expected amount. This a measure by a ratio, therefore anything above 1 is bad and anything below 1 is good. The MSPB measure of below 1 means that the hospital is not losing any money by not spending as much as they initially expected. Having a measure of means that the adjusted amount and the expected cost are roughly the same and the hospital will not be losing any money. Any value above 1 result in a loss of money to the hospital because the expected amount was less than the actual adjusted amount. The average spending per episode at the local hospital is \$21,404.04 and the MSPB amount is \$20,971.38" (Bowers et al., 2018). Reduction of costs by 1/100<sup>th</sup> does not appear to be significant savings, but when the savings is totaled over the course of one year it can save hospitals millions of dollars.

Another study published in 2018 compared advanced care planning (ACP) with a similar control group using accountable care organization (ACO) data. This study also focuses on the decrease of Medicare costs associated with end-of-life patients in the last six months of life. The ACO is a multistate healthcare system that serves approximately 3 million people. It includes 11 hospitals, 75 outpatient practices and over 18,000 employees. The study performed by Bischoff et al. examined the association of outpatient ACP with advance directive documentation rates, utilization, and costs in a cohort of patients who died compared to matched controls using accountable care organization (ACO) data. The ACO made considerable investments in the ACP process to improve access, including efforts to improve the number and qualifications of ACP facilitators, over the time period 2008 to present. The study was conducted as a case-control study with patients with ACP serving as cases, and those without ACP serving as matched controls using three data sources: (1) ACO data, (2) an ACP facilitator logging database (Instant Data Entry Application [IDEA] v4.4; Health Catalyst, Salt Lake City, UT), and (3) EPIC<sup>a</sup> Electronic Medical Record (EMR) data. This study was approved by the regional institutional review board and we received permission from CMS to use ACO data for research purposes. The ACO data covered January 2013 to the end of April 2016. The ACO is multisite healthcare system serving a catchment area of nearly 3 million people that includes 11 hospitals, 75 outpatient practices, and more than 18,000 employees. The results regarding ACP and documentation rates are consistent with a recent systematic review without metanalysis by Brinkman-Stoppelenburg et al., which found a positive impact of ACP on after death completion rates and compliance with end-of-life wishes. It was reported was that "overall costs were less by \$9,500. This was driven primarily by a reduction in inpatient utilization and did not appear to be due to increased hospice service use. There are few randomized trials of the impact of ACP on overall costs. Molloy et al. studied the impact of ACP-like discussions surrounding nursing home residents in Canada and found reductions in hospital days along with reduction in costs of \$1,748.35 Canadian dollars. Engelhardt et al. assessed the impact of care coordination and assisting with ADs in high-risk patients and found that six-month costs were lower by \$4,172, which did not reach statistical significance, but over 40% in both groups were alive at study conclusion" (Bond et al., 2018). A telephone trial winch included end-of-life counseling by nurses was also analyzed during the study. It was found that Medicare costs were 1,913 US dollars lower in the group that received intervention over the last six months of life. Along with the decreased Medicare costs, a retrospective cohort study of 54 intervention and 108 control patients found advance directives completed in 98% of their Palliative Care Homebound Program (includes ACP elements) versus 31% of controls" (Bischoff

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et al., 2014). ACP has been associated with less risk for in-hospital death, and more often associated with Hospice or palliative care team utilization. This study did not include many cancer patients and reflected a lower amount of ACP found in the cancer patients that were included. This could mean that cancer patients are either using a separate system, or there is a need for more integrative education and discussion with this specific group of patients. Since terminally diagnosed patients have higher OOP costs than most treatments, lowering OOP costs for patients is beneficial. This specific study also utilized one health care system, which resulted in a limited representation of minority groups. As stated earlier, "U.S. people who are from minority racial and ethnic groups are less likely to have engaged in death preparation" (Kelley et al., 2010). Use of a more ethnically diverse population may lower the number of ACP found that correlate to less spending in the last six months of life.

#### **CHAPTER 5**

#### **RESPONSIBILITY OF PATIENT EDUCATION**

"More than 80 percent of the deaths in the United States occur with at least several weeks' warning, and in most cases health care professionals will have been involved. Whether death occurs at home or in an institution, there is a period during which health professionals have multiple opportunities to help the soon-to-bebereaved" (Osterweis, 1984). By ensuring that the patient and family are made as comfortable as possible during this generally difficult time, staff members establish themselves as people who will help the survivors. End of life preparation with patients has often been left to the spiritual educators. Clergy that is employed by the hospital or facility, or the patient's personal clergy member, would be tasked to discuss things like funeral plans and last wishes. The doctors that are working with the patients are usually responsible for discussing end of life measures when it comes to things such as Physician Orders for Life Sustaining Treatment (POLST) forms. Forms such as POLST address issues pertaining to hospitalizations and include informed patient decisions pertaining to ventilator use, resuscitation orders, tube feeding, and comfort care. These forms and discussions are more pertinent to a patient's autonomy and wishes during their end of life process. The financial aspects of ICU stays associated with ventilator use and cardiopulmonary resuscitation (CPR) are not addressed. The financial burden may influence the decisions that terminal patients make when filling out POLST forms with their physicians, but only if they have the knowledge of what life sustaining treatments cost. More recently, hospitals have introduced palliative care staff. The National Consensus Project for Quality Palliative Care describes palliative care as "optimizing quality of life by anticipating, preventing, and treating suffering as patients and their families face life-threatening illness or disease. Typically, palliative care is available throughout the course of debilitating, progressive, and terminal illnesses/diseases and injuries. Care focuses on the physical, intellectual, emotional, social, and spiritual needs of patients and families" (NCPQPC, 2013). With no legal or financial education included in the palliative care team the patient (and the family's) social, emotional or intellectual needs are not being fully met. The focus on grief and acceptance is important from an economic perspective. It allows family members to return to the roles of productive, wage earning members of society more quickly. Viewing this from a human capital approach, it is necessary to have the generated income and contributions that are often delayed when an individual suffers from loss, resulting in extended grieving periods.

Social workers are often involved directly with patients in the hospital setting. Social workers are innovative and willing to form partnerships with other community leaders and professionals, and these interventions may lead to new community services to address the last stage of life (e.g., Kintzle & Bride, 2010). Social workers tend to deal with financial aspects when it comes to placement in skilled nursing facilities (SNF) and when working to provide patients with home health staff. Social workers are often found in the hospital setting and in Hospice or palliative care teams. A study done by Osterweis in 1984 looked at the education that is relevant to a more integrative approach with patients. Osterweis states, "a social worker in the health field ordinarily prepares in the clinical track that emphasizes interpersonal skills in individual and group interviewing and with the goal of restoring, enhancing, or maintaining social functioning. Social work curricula always include course work on dying and death using content about the physical, emotional, and social problems faced at various points in the life cycle" (Osterweis, 1984). Social workers are trained to deal with grief, loss and social problems. They do not currently have integrative training for the economic or financial skill to educate patients when it concerns economic or legal issues that will happen during or after the death process.

Nurses are also trained in concepts and skills to deal with crisis, loss, grief, death, and bereavement. They often do not know what the cost of ICU stays, extended care and life sustaining treatments total. The nurse is a highly trained professional but is lacking the financial and legal training when it comes to educating patients who are facing impeding death.

All professionals that work with patients have skills, but who is capable of educating patients and their families in all the varying areas of impending death? Integrative social science is a new field offered from a variety of schools. Penn State explains that "integrated social sciences encompass the study of society and relationships among individuals and institutions. The course work draws on core social science disciplines of anthropology, communication arts and sciences, economics, political science, psychology, and sociology". Arizona State University explains that integrative social scientist will develop foundations in areas such as "research analysis, public administration, policy analysis, sustainability, business and environmental affairs, organizational management, and community college teaching" (CISA, 2020). By utilizing multiple theories and skill sets, death educators could focus on the many facets of pre and post death planning. If focus is shifted to an integrative approach, hospitals may better prepare the patients for the financial and legal outcomes of terminal illness and ultimately death while still offering the social, emotional, physical, spiritual and intellectual needs that are currently being offered.

#### CHAPTER 6

#### CONCLUSION

The legal and economic costs of death are not something normally addressed with patients prior to the occurrence of death. With an integrative approach, education may help reduce financial stressors for the family, while offering cost saving benefits to the facilities involved. This paper addresses the need for integrative education pertaining to the humanistic and economic aspects of death concerning the terminally diagnosed patient. It has shown that educational services currently being utilized in hospitals need to be well rounded, including both financial and legal education for patients and their families. Using an integrative approach when meeting with terminal patients, they will receive a much more well-rounded education. Offering financial and legal education to patients with terminal illnesses may reduce hospital visits and lower costs, reducing stress and anxiety that may accompany a terminal diagnosis.

#### REFERENCES

- Adorno, G., & Wallace, C. (2017). Preparation for the end of life and life completion during late-stage lung cancer: An exploratory analysis. Palliative & supportive care, 15(5), 554-564.
- American Institute for Cancer Research. (2017). Prevent Cancer, Prevent \$158 Billion in Healthcare Costs. Retrieved from https://www.aicr.org/resources /blog/prevent-cancer-prevent-158-billion-in-healthcare-costs/
- Arizona State University College of Integrative Arts and Sciences. (2020). MS in Integrative Social Science. Retrieved from https://cisa.asu.edu/msintegrative- social-science
- Bao, Y., Maciejewski, R. C., Garrido, M. M., Shah, M. A., Maciejewski, P. K., & Prigerson, H. G. (2018). Chemotherapy use, end-of-life care, and costs of care among patients diagnosed with Stage IV pancreatic cancer. Journal of pain and symptom management, 55(4), 1113-1121.
- Bekelman, J. E., Halpern, S. D., Blankart, C. R., Bynum, J. P., Cohen, J., Fowler, R., ... & Oosterveld-Vlug, M. (2016). Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. Jama, 315(3), 272-283.
- Bergstrom, R. (2012). Drivers of the cost of cancer care. Lancet Oncology, 13(1), 14-15.
- Biondo, P. D., Lee, L. D., Davison, S. N., Simon, J. E., & Advance Care Planning Collaborative Research and Innovation Opportunities Program (ACP CRIO). (2016). How healthcare systems evaluate their advance care planning initiatives: results from a systematic review. Palliative medicine, 30(8), 720-729.
- Bond, W. F., Kim, M., Franciskovich, C. M., Weinberg, J. E., Svendsen, J. D., Fehr, L. S., ... & Asche, C. V. (2018). Advance care planning in an accountable care organization is associated with increased advanced directive documentation and decreased costs. Journal of palliative medicine, 21(4), 489-502.

- Bowers, N., Cirelli, J., Andrzejewski, A., Lang, J., Aqlan, F., & Pedersen, A. (2018, January). Analysis of Medicare Spending Per Beneficiary (MSPB).
   In Proceedings of the International Conference on Industrial Engineering and Operations Management (Vol. 2018, No. SEP, pp. 1171-1179).
- Brown, M. L., & Yabroff, K. R. (2006). 12, Economic impact of cancer in the United States. Cancer epidemiology and prevention, 202.
- Brumley, R., Enguidanos, S., Jamison, P., Seitz, R., Morgenstern, N., Saito, S., ...
  & Gonzalez, J. (2007). Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. Journal of the American Geriatrics Society, 55(7), 993-1000.
- Brustugun, O. T., Møller, B., & Helland, Å. (2014). Years of life lost as a measure of cancer burden on a national level. British journal of cancer, 111(5), 1014-1020.
- Carr, D. (2012). Death and dying in the contemporary United States: What are the psychological implications of anticipated death? Social and Personality Psychology Compass, 6(2), 184-195.
- Corden, A., & Hirst, M. (2008). Implementing a mixed methods approach to explore the financial implications of death of a life partner. Journal of Mixed Methods Research, 2(3), 208-220.
- DiGiacomo, M., Lewis, J., Phillips, J., Nolan, M., & Davidson, P. M. (2015). The business of death: a qualitative study of financial concerns of widowed older women. BMC women's health, 15(1), 36.
- French, E. B., McCauley, J., Aragon, M., Bakx, P., Chalkley, M., Chen, S. H., ... & Fan, E. (2017). End-of-life medical spending in last twelve months of life is lower than previously reported. Health Affairs, 36(7), 1211-1217.
- Garrido, M. M., Prigerson, H. G., Bao, Y., & Maciejewski, P. K. (2016). Chemotherapy use in the months before death and estimated costs of care in the last week of life. Journal of pain and symptom management, 51(5), 875-881.

- Hammes, B. J., & Rooney, B. L. (1998). Death and end-of-life planning in one midwestern community. Archives of Internal Medicine, 158(4), 383-390.
- Harper, S. (2014). Economic and social implications of aging societies. Science, 346, 587-591. doi:10.1126/science.1254405
- Jung, H. M., Kim, J., Heo, D. S., & Baek, S. K. (2012). Health economics of a palliative care unit for terminal cancer patients: a retrospective cohort study. Supportive Care in Cancer, 20(1), 29-37.
- John, R., & Ross, H. (2010). The global economic cost of cancer. Atlanta, GA: American Cancer Society and LIVESTRONG.
- Johnson, K. J., Hong, M., Inoue, M., & Adamek, M. E. (2016). Social work should be more proactive in addressing the need to plan for end of life.
- Kelley, A. S., Wenger, N., & Sarkisian, C. (2010), Opiniones: End-of-life care preferences and planning of older Latinos. Journal of the American Geriatrics Society, 58, 1109–1116. doi: 10.1111/j.1532-5415.2010.02853.x
- Kess, S., Grimaldi, J. R., & Revels, J. A. (2018). Planning During Terminal Illness. The CPA Journal, 88(5), 32-37.
- Klingler, C., in der Schmitten, J., & Marckmann, G. (2016). Does facilitated advance care planning reduce the costs of care near the end of life? Systematic review and ethical considerations. Palliative medicine, 30(5), 423-433.
- Kivimäki, M., Vahtera, J., Elovainio, M., Lillrank, B., & Kevin, M. V. (2002). Death or illness of a family member, violence, interpersonal conflict, and financial difficulties as predictors of sickness absence: longitudinal cohort study on psychological and behavioral links. Psychosomatic medicine, 64(5), 817-825.
- Massachusetts General Hospital. (2020). A Checklist of Tasks After Death. Retrieved from https://www.massgeneral.org/medicine/pcgm/palliativecare/resources/checklist

- McCarthy, E. P., Phillips, R. S., Zhong, Z., Drews, R. E., & Lynn, J. (2000). Dying with cancer: patients' function, symptoms, and care preferences as death approaches. Journal of the American Geriatrics Society, 48(S1), S110-S121.
- Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): literature review and a call for research and public dialogue. The American Journal of Geriatric Psychiatry, 24(4), 261-271.
- Miller, S., & Belizán, J. M. (2015). The true cost of maternal death: individual tragedy impacts family, community and nations. Reproductive health, 12(1), 56.
- Mystakidou, K., Parpa, E., Katsouda, E., Galanos, A., & Vlahos, L. (2004). Influence of pain and quality of life on desire for hastened death in patients with advanced cancer. International journal of palliative nursing, 10(10), 476-483.
- National Funeral Directors Association. (2019). Statistics. Retrieved from https://www.nfda.org/news/statistics
- National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. 3rd ed. Pittsburgh PA: National Coalition for Hospice and Palliative Care; 2013
- Osterweis, M., Solomon, F., & Green, M. (1984). Reactions to particular types of bereavement. In Bereavement: Reactions, consequences, and care. National Academies Press (US).
- Pew Research Center. (2013). Views on end-of-life medical treatments. Retrieved from http://www.pewforum.org/2013/11/21/views-on-end-of-life medical-treatments/
- Prelock, P. A., Melvin, C., Lemieux, N., Melekis, K., Velleman, S., & Favro, M. A. (2017, November). One Team–patient, family, and health care providers: An interprofessional education activity providing collaborative and palliative care. In Seminars in speech and language (Vol. 38, No. 05, pp. 350-359). Thieme Medical Publishers.

- Rodenbach, R. A., Rodenbach, K. E., Tejani, M. A., & Epstein, R. M. (2016). Relationships between personal attitudes about death and communication with terminally ill patients: How oncology clinicians grapple with mortality. Patient education and counseling, 99(3), 356-363.
- Schmit, J. M., Meyer, L. E., Duff, J. M., Dai, Y., Zou, F., & Close, J. L. (2016). Perspectives on death and dying: a study of resident comfort with End-oflife care. BMC medical education, 16(1), 297.
- Scitovsky, A. A. (2005). "The high cost of dying": what do the data show? The Milbank Quarterly, 83(4), 825.
- Sudore, R. L., & Fried, T. R. (2010). Redefining the "planning" in advance care planning: preparing for end-of-life decision making. Annals of internal medicine, 153(4), 256-261.
- Tang, S. T., Chang, W. C., Chen, J. S., Wang, H. M., Shen, W. C., Li, C. Y., & Liao, Y. C. (2013). Course and predictors of depressive symptoms among family caregivers of terminally ill cancer patients until their death. Psycho-Oncology, 22(6), 1312-1318.
- Tang, S. T., Liu, T. W., Tsai, C. M., Wang, C. H., Chang, G. C., & Liu, L. N. (2008). Patient awareness of prognosis, patient–family caregiver congruence on the preferred place of death, and caregiving burden of families contribute to the quality of life for terminally ill cancer patients in Taiwan. Psycho-Oncology, 17(12), 1202-1209
- Tilden, V. P., Tolle, S. W., Drach, L. L., & Perrin, N. A. (2004). Out-of-hospital death: advance care planning, decedent symptoms, and caregiver burden. Journal of the American Geriatrics Society, 52(4), 532-539.
- Treacy, J. T., & Mayer, D. K. (2000, February). Perspectives on cancer patient education. In Seminars in oncology nursing (Vol. 16, No. 1, pp. 47-56). WB Saunders.
- University of California San Francisco. (2020). Practical Tasks Following Death. Retrieved from https://www.ucsfhealth.org/education/practical-tasksfollowing-death

Zimmermann, C., & Rodin, G. (2004). The denial of death thesis: sociological critique and implications for palliative care. Palliative medicine, 18(2), 121-128.

## APPENDIX A

A CHECKLIST OF TASKS AFTER DEATH

The following is a list of tasks that are likely to need attention:

If your loved one was a veteran, you may be able to get assistance with the funeral, burial plot or other benefits. For information on benefits call the Veterans Administration at 800-827-1000. Also, the phone number for your local Veterans Agency is usually listed under Town Offices. You will need a copy of your loved one's discharge papers. In most cases these can be obtained from Massachusetts War Records, 617-727-2964.

Obtain 10-15 copies of the Death Certificate from your funeral director. You can also get additional copies later online at: www.vitalrec.com/ma.html or at your city hall.

If your loved one was receiving Social Security benefits, notify your local Social Security office of the death, since these benefits will stop. Overpayments will result in a difficult process of repayment. If you are a surviving spouse, ask about your eligibility for increased benefits. Also, check on benefits that any minor children may be entitled to receive.

Contact the health insurance company or employer regarding terminating coverage for the deceased while continuing coverage for others covered through the policy.

Contact the insurance company for all life insurance policies. You will need to provide the policy number and a certified copy of the death certificate and fill out a claim form. If the deceased is listed as the beneficiary on any other policy, arrange to have the name removed.

If the deceased was working, contact the employer for information on pension plans, credit unions and union death benefits. You will need a certified copy of the death certificate for each claim.

Return credit cards of the deceased with a certified copy of the death certificate, or notify the credit card company if you, as the survivor, want to retain use of the card.

Seek the advice of an accountant or tax advisor about filing the deceased's tax return for the year of the death. Keep monthly bank statements on all individual and joint accounts that show the account balance on the day of death, since you will need this information for the estate tax return.

Arrange to change any joint bank accounts into your name. If the deceased's estate is in trust, check with the Trust Department or Customer Service at the bank.

If the deceased owned a car, transfer the automobile title into your name at the Secretary of State's Office, or if the estate is probated, through Probate Court. Arrange to change stocks and bonds into your name. Your bank or stockbroker will have the forms.

Make sure that important bills, such as mortgage payments, continue to be paid.

Documents you may need to complete these tasks: Death Certificates (10 - 15 certified copies) Social Security Card Marriage Certificate Birth Certificate Birth Certificate for each child, if applicable Insurance Policies Deed and Titles to Property Stock Certificates Bank Books Honorable Discharge Papers for a Veteran and/or V.A. Claim Number Recent Income Tax Forms and W-2 Forms Automobile Title and Registration Papers Loan and Installment Payment Books and/or Contracts

## APPENDIX B

PRACTICAL TASKS FOLLOWING DEATH

#### University of California San Francisco

#### Practical Tasks Following Death

After the death of a loved one, there are many practical tasks that will need your attention. This is a challenging and exhausting time, and it is a good idea to enlist the help of a family member or friend.

#### Who to Notify

Below is a list of people and groups to notify after the death of your loved one. You will likely need to provide death certificates to some of them. If your spouse has passed away, you may also need copies of your marriage certificate.

The best way to obtain a death certificate is through the funeral home; they can also advise you on how many you may need, as copies generally aren't accepted. It will take the funeral home one to two weeks to prepare and process death certificates.

It is helpful to bring the following information with you when you visit the funeral home:

Name of the deceased Date and place of birth Social security number Father's full name and place of birth Mother's full name and place of birth Please notify the following:

Those involved in funeral arrangements:

Funeral director of funeral home (to arrange services) Church, temple, mosque or place of worship (to arrange services) Cemetery or memorial park Organist, singer, pallbearers Relatives and friends

Banks or credit unions

Joint accounts are automatically closed after the joint account holder notifies the bank of the death. Request that your bank release the funds to you. You should immediately establish a new account to handle funds received after the death.

If a safety deposit box was rented in the name of the deceased only, you will need a court order to open it.

Insurance companies (health, life, auto)

If the funds are not already committed to a financial plan, request payment for only the amount you will need in the next two months. Leave decisions about investments for a later, less harried time. Call the companies for forms.

Social Security, veteran's benefits, pension/association programs

The death benefits that are part of these plans should be applied for promptly. See the "Death Benefits" section below for more information.

#### Probate court

In most states, wills must be filed within 10 days or, if there is no will, this act must be disclosed. Probate procedures may be a complex matter, depending on the size of the estate and claims against it. The advice of a family lawyer or wise friend who has been through the process is invaluable. If the surviving spouse can be appointed administrator of the estate, this arrangement often saves money.

Be aware that the court generally does not permit probate to be concluded in less than a year, so some resources may be tied up for at least that long.

If you need legal assistance, contact the County Bar Association Lawyer Referral Service at (415) 989-1616 or visit the American Bar Association website.

Hospitalization/Major medical insurance

Spouses of the deceased must either convert to an individual medical insurance plan or purchase their own personal policy.

Unions, fraternal organizations, alumni associations, professional societies and other organizations

Newspapers for obituary, if desired

Credit card companies

Cancel credit cards that are only in the name of the deceased.

Automotive groups

Transfer the titles of any cars that were in the name of the deceased. Contact the Department of Motor Vehicles for details. Notify auto insurance companies.

Compiling Important Documents While settling affairs for your loved one, it is helpful to have some of these documents on hand:

Social security card Citizenship documents Will or living trust Insurance policies Deeds to properties Titles to automobiles, boats or RVs Bank books Stock, bond or mutual fund statements IRA, 401(k) or pension plan information Income tax returns Disability claims Death Benefits Social Security offers death benefits to a surviving spouse, or, if there is no surviving spouse, an eligible child. Certain family members may also be eligible for benefits. The death benefit is a one-time sum of \$255.

Death benefits may also include Veterans Administration, insurance, employee pension and union or fraternal organization benefits.

Other Practical Tasks Wills If you included the deceased in your will, you will want to update it.

Income tax

Income taxes still need to be filed for the deceased for that year. Taxes are due on the normal filing date, but you can request an extension. If the deceased was your spouse, you can still file jointly. If you have dependent children, you can file a joint return for two more years.

Federal estate tax return (IRS Form 706) Check with the IRS, a tax consultant or online to see if you will need to file for a federal estate tax return. If you do need to file for this, you should do it within nine months of the death.

### APPENDIX C

# NATIONAL MEDIAN COST OF FUNERAL WITH CREMATION

National Median Cost of an Adult Funeral with Viewing and Cremation

Item	2017*	2014*
Nondeclinable basic services fee	\$2,100	\$2,000
Removal/transfer of remains to funeral home	\$325	\$310
Embalming	\$725	\$695
Other preparation of the body	\$250	\$250
Use of facilities/staff for viewing	\$425	\$420
Use of facilities/staff for funeral ceremony	\$500	\$495
Service car/van	\$150	\$143
Basic memorial printed package	\$160	\$155
Cremation fee (if firm uses a third-party	\$350	\$330
crematory)**		
Cremation casket	\$1,000	\$1,000
Urn	\$275	\$280
Median Cost of a Funeral with Viewing and	\$6,260	\$6,078
Cremation		

\* Median Price – The amount at which half of the figures fall below and half are above.

\*\*69% of respondents use a third-party crematory (i.e., the funeral home does not own a crematory)

## APPENDIX D

# NATIONAL MEDIAN COST OF FUNERAL WITH BURIAL

National Median Cost of an Adult Funeral with Viewing and Burial: 2017 vs. 2014

2017\*

\$2,100

\$325

\$725

\$250

\$425

\$500

\$325

\$150

\$160

\$2,400

\$7,360

\$1,395

\$8,755

2014\*

\$310

\$695

\$250

\$420

\$495

\$318

\$143

\$155

\$2,395

\$7,181

\$1,327

\$8,508

\$2,000

Item

Nondeclinable basic services fee

Removal/transfer of remains to funeral home

Embalming

Other preparation of the body

Use of facilities/staff for viewing

Use of facilities/staff for funeral ceremony Hearse

Service car/van

Basic memorial printed package

Metal casket

Median Cost of a Funeral With Viewing and Burial

Vault

Total with vault

2014 prices have not been adjusted for inflation.

\* Median Price – The amount at which half of the figures fall below and half are above.