Cicely Saunders and the Hospice Movement: 
*Changing the Tragedy of Dying into a Triumph*

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*Individual Junior Paper*  

2367 words
“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

-Cicely Saunders

People of all cultures throughout history have been linked by one common thread. We all eventually will die. For centuries death was a similar experience for humankind. It was a natural part of life that could not be delayed or halted. Our pioneer ancestors typically died at home supported by family and community. However, with advances in medical care in the 20th century the dying process could be prolonged or even prevented. While this was a triumph in many ways, use of modern medical treatments for the terminally ill often resulted in extended pain and suffering, creating an unintended tragedy.  

In addition, death started occurring in hospitals in a more unnatural way without the personal care of family and friends. In response to this tragedy, Cicely Saunders, an English nurse, social worker, and physician, pioneered the modern hospice movement. The movement empowered people all over the world by helping people decide how they wanted to live before they died, giving them a more comfortable, peaceful, natural, and dignified death.

Before the 20th century, most people in the United States (U.S.) died at home fairly quickly and almost always surrounded by family. Communities were typically small and neighbors, friends, and family of the dying person cared for and supported the dying person. In

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addition, they cared for the family who was coping with the reality that their loved one would soon die.⁵ However, as medical technology rapidly advanced in the 1900s things changed.

As a result of revolutionary inventions in medicine, death could often be prevented. For example, in 1928 Alexander Fleming discovered the first antibiotic, penicillin.⁶ As the use of antibiotics evolved, infection, which caused about 33 percent of all deaths at the beginning of the 20th century, caused only about four percent of all deaths at the end of the century.⁷ This was one of many medical triumphs.

In 1928, Philip Drinker and Louis Agassiz Shaw developed the tank respirator also known as the iron lung.⁸ It helped people breath when they could not breathe on their own due to diseases such as polio. Later versions called ventilators kept people alive even more effectively during severe illness as well as surgery.⁹ In 1953, Bjorn Ibsen created the first intensive care unit. It was a dedicated hospital ward in which the very sick were cared for, each by their own nurse, often with the use of ventilators.¹⁰ Hospitals, once a place of hopelessness, became a place to cure disease and make people well.

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⁵ Consider the Conversation. Produced by Terry Kaldhusdal, 2011.
⁹ "Mechanical Ventilators." Science Museum Brought to Life Exploring the History of Medicine, broughttolife.sciencemuseum.org.uk/broughttolife/techniques/mechanicalventilators.
“Today, hospitals are central to the delivery of medical and surgical care. However, in past centuries most people would have avoided entering them. Hospitals were often a place of ‘last resort’ associated with poverty, infection, and death.”

Average life expectancy changed from 47.3 years at the turn of the 20th century to 76.7 years at the end of the century. In addition, more people were dying slowly because the leading causes of death changed from infectious diseases to heart disease and cancer. By the mid 20th century most people died in hospitals. Death was increasingly viewed as a failure by the medical community. Death became institutionalized and people no longer died at home. Now, they often died hooked up to machines without the personal care of family and community. This was a turning point in medicine in how we live at the end of our lives. Cicely Saunders, who lived for most of the 20th century, witnessed the many triumphs in medicine as well as the tragic byproduct of these triumphs. As her life progressed Saunders left her own legacy of change and triumph for 20th-century medicine through the development of modern hospice.

Cicely Saunders was born on June 22, 1918, in England. She was the oldest of three children born into a prosperous family. In 1938 she completed her philosophy, politics and

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16 Kiernan, telephone interview by the author.
economics degrees at St. Anne’s College, part of the University of Oxford. However, during World War II she wanted to do something more useful so she enrolled in nursing school at St. Thomas’s Hospital and completed her degree in 1944. Saunders then returned to St. Anne’s and pursued a degree as a Lady Almoner, or social worker.\textsuperscript{17}

As a Lady Almoner, Saunders helped poor patients who were in the hospital arrange for aftercare. She also volunteered as a nurse during this time.\textsuperscript{18} Saunders had a special interest in helping the terminally ill. She observed that hospitals were designed for people with illnesses and injuries which could be cured. They were not well equipped to help people who were in pain and dying slowly. Saunders was troubled by the lack of adequate pain control.\textsuperscript{19} Painkillers were rarely used because they were considered to be dangerous and addictive.\textsuperscript{20} In addition, she was concerned by the medical community’s lack of support in helping dying patients. During this time she was inspired by one of her patients to challenge current practices and initiate change.\textsuperscript{21}

In 1947, Saunders cared for a young Jewish man named David Tasma\textsuperscript{22} who was dying of cancer.\textsuperscript{23} He asked for three things from Saunders as his caregiver. First, he wanted openness of communication. Second, he said, “I want what is in your mind and in your heart”. Third, he asked for freedom of spirit. Based on these insights, Saunders established three principles of hospice care including maintaining openness, caring with mind as well as heart by combining skilled medical care with compassion, and allowing each individual to make his or her own

\textsuperscript{17} "Better Care at the End of Life." Cicely Saunders International, cicelysaundersinternational.org/.
\textsuperscript{19} "Better Care at the End of Life." Cicely Saunders International, cicelysaundersinternational.org/.
\textsuperscript{21} "Better Care at the End of Life." Cicely Saunders International, cicelysaundersinternational.org/.
\textsuperscript{22} Jacson, Avril, and Ann Eve. Hospice Care on the International Scene. Edited by Cicely Saunders and Robert Kastenbaum, 4.
personalized journey towards their end of life goals.\textsuperscript{24} She set out to transform medical care for the dying using these three principles as pillars.

Saunders shared her goal with the surgeon for whom she was working. He said, “Go and read medicine,” meaning go and become a doctor, because, he added, “It’s the doctors who desert the dying.” Therefore, at the age of 31, she pursued her degree as a doctor with the hope of changing how the medical community cared for the dying.\textsuperscript{25}

Cicely Saunders graduated from St. Thomas’s Medical School in 1957. In 1958 she received a research scholarship to work in London on pain control for terminally ill, many of whom had cancer. This was a turning point in her career. As part of her research, she took pictures of patients before they received adequate pain control, and then again after they received adequate pain control. The comparisons between the two were striking. She recognized that there was a desperate need for much more research on how to help the dying.\textsuperscript{26} Saunders envisioned a modern hospice facility dedicated to specialized clinical care of the dying, scientific research focusing on how to help dying patients and further education of other professionals.\textsuperscript{27}

The words hospice and hospitality come from the same Latin word “hospes”, which refers to a traveling guest or traveler’s host. The Crusaders of the 11th century are believed to be the first to set up homes for the terminally ill. In the 14th century hospices were a place of refuge for tired or sick travelers. Religious groups provided hospice for the dying for centuries. This

\textsuperscript{24} Jacson, Avril, and Ann Eve. Hospice Care on the International Scene. Edited by Cicely Saunders and Robert Kastenbaum, 4.
\textsuperscript{25} “Better Care at the End of Life.” Cicely Saunders International, cicelysaundersinternational.org/.
\textsuperscript{26} Boulay, Cicely Saunders, 239-240.
care was directed towards poor people who had no family. Saunders was the first to apply the name hospice to specialized medical care for the dying when she pioneered the first modern hospice center.

In 1963, Saunders started a fundraising campaign to build the center. By 1965 she had the funds to proceed and the first modern hospice was opened in 1967 in England. It was called St. Christopher’s Hospice and had space for 54 patients. This was the start of a transformation in how the modern world perceived the dying process and cared for those who were terminally ill.

While striving to fund and open St. Christopher’s Hospice, Cicely Saunders also shared her knowledge and goals with the medical community. She wrote about her experiences with the dying. She traveled to give lectures to colleagues and caregivers. Saunders also authored many professional papers about her research and ideas.

These efforts included a trip to the U.S. where she shared her pictures and research on pain control and championed the cause for change. During her first trip to the U.S., she spent eight weeks in the U.S. and visited 18 different hospitals and academic centers. She met with doctors, social workers, nurses, psychiatrists, scientists, and chaplains. She forged many relationships with many influential medical professionals. She stayed connected with these colleagues through letters and medical journal publications as well as a St. Christopher’s Hospice newsletter, which she started and distributed once it was opened. She was featured in articles in U.S. newspapers and magazines such as Harper’s Magazine and Time magazine. Her work and

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30 “Better Care at the End of Life.” Cicely Saunders International, cicelysaundersinternational.org/.
ideas were blanketing the country. Her initiatives on caring for a dying person’s “total” pain, including physical, mental, social and spiritual began sparking change in the U.S.\textsuperscript{32}

Saunders connected with important leaders during her travels in the U.S., one of which was Florence Wald who was Dean of Yale University Nursing School. Wald was inspired by Saunders. She visited St. Christopher’s Hospice and returned to the U.S. to start the first modern hospice, called Connecticut Hospice.\textsuperscript{33}

Multiple hospice programs stemmed from those early efforts. However, progress was difficult. People were unfamiliar with modern medical treatments and modern hospice treatments. Health professionals often lacked compassion towards the dying. People in general, both health care providers and patients did not openly communicate about death.\textsuperscript{34} Psychiatrist Elisabeth Kubler-Ross, a 20th-century pioneer in the study of death and dying noted “We live in a very particular death-denying society. We isolate both the dying and old, and it serves a purpose. They are reminders of our own mortality.”\textsuperscript{35} Even amidst these challenges with society’s attitudes towards death and dying, Saunders persevered and continued to guide and inspire physicians, social workers, nurses, scientists, pastors, patients, and families to establish modern hospice care.

Hospice care evolved and took on many forms. The number of independent hospice facilities was expanding in the U.S. Some hospitals created dedicated hospice units.\textsuperscript{36} “Home”

\textsuperscript{32} "Better Care at the End of Life." Cicely Saunders International, cicelysaundersinternational.org/.
\textsuperscript{34} "Better Care at the End of Life." Cicely Saunders International, cicelysaundersinternational.org/.
hospice care also was being provided in nursing homes and people’s homes. The modern hospice care movement pioneered by Saunders in the U.S. continued to make great strides as the movement became more organized and policies changed to support hospice care.

“What was astonishing about her achievement in the late 1950s was two things: she was trying to focus attention on care of dying, a field that no one cared about, and she was doing it as a woman in a heavily male-dominated profession”, said David Clark, a historian at Lancaster University, United Kingdom.

In 1978 the National Hospice Organization was formed, now called the National Hospice and Palliative Care Organization. Its mission has been “to lead and mobilize social change for improved care at the end of life”. In 1982 Congress voted to create a hospice benefit so that people insured by Medicare, mainly the old, could have this care covered by their health insurance. In 1993, healthcare changes resulted in hospice becoming an accepted part of usual health care needs. This was a major cultural change. The court system also was addressing end of life challenges. For example, beginning in 1975, an unconscious Karen Ann Quinlan was kept alive for 10 years with life support equipment. Her story became a national tragedy and a cautionary tale. Doctors were unwilling to stop the life support and the court ruled on her behalf that she should be allowed to be taken off life support and die naturally.

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38 On Dying Well, 52.
The hospice care movement has continued to grow and expand even after Saunder’s death. In 2015, about ninety percent of hospitals in the US with three hundred beds or more offered palliative care services. In 2016, 1.43 million patients received hospice care in the U.S. Forty-eight percent of Medicare patients were enrolled in hospice at the time of death and there were 4,382 hospice care programs certified through Medicare in the U.S. In addition, to the implementation of hospice care itself, Saunders’ work has impacted U.S. culture and society in many other ways.

Hospice has helped not only the dying but also the families of the dying both during and after the death of their loved one with bereavement support. Also, the financial burden often experienced by families as a result of costly end of life care has been decreased as hospice has become more acceptable by the medical community and more accessible to the dying. Additionally, the cost to society as a whole is less. In 2016, the average cost for the last month of life when dying at home was $4,760 compared to $32,379 when dying in a hospital. Furthermore, the hospice movement has resulted in more open discussion and planning for death through advanced directives, which allow people to choose which medical interventions they want in the event of serious illness and removes this difficult and emotional decision from the shoulders of family members.

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44 "Kiernan, telephone interview by the author.
46 Kiernan, telephone interview by the author.
The technological developments of modern medicine in the 20th century resulted in many triumphs for humanity. However, use of modern technological advancements for the terminally ill resulted in extended pain and suffering creating an unintended tragedy. Cicely Saunders witnessed the tragic institutionalization of death and pioneered the modern hospice movement leaving a legacy of triumph. She identified the desperate need of the dying to receive better care, including total pain control and care of the whole patient. She conducted scientific research to define their needs and treatments. She educated the world on her studies and ideas and helped guide others to implement similar initiatives in their own communities. In doing so, Saunders helped millions of terminally ill people live the last part of their lives well, and die a more dignified, comfortable and peaceful death. Her hospice innovations are still growing and evolving today and continue to change the culture of dying for the terminally ill from tragedy to triumph.
Appendix 1

This photograph shows what St. Christopher's Hospice looked like while being built between 1965 and 1967.
Appendix 2

This photograph shows a four bed ward in the original St. Christopher's Hospice in 1967.
This photograph shows Cicely Saunders with one of her patients.
Works Cited

Primary Sources

This source gave me many resources and photographs relating to St. Christopher's Hospice and Cicely Saunders.

This source gave me a good understanding on what was being reported in the news about the Terri Schiavo case at the time.

This source gave me a lot of good information about Sauner’s life. In addition, the afterword, written by Saunders, provided detailed insight into her thoughts and philosophy.

This source helped me better understand Saunders's life and how different factors throughout her life influenced her in different ways.

This source helped me understand how life expectancy rates have increased significantly in the last century.

This book provided perspective on Saunders's philosophy and strategies towards hospice care.

This book provided firsthand information from Saunders herself about her philosophy on hospice care and her goals to continue to expand it internationally

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This article helped me better understand the tragedy of prolonging life in futile situations. It also provided historical context for the day Quinlan died.

Saunders, Cicely. *Beyond the Horizon*. London, Darton, Longman, and Todd Limited, 1990. This book included many firsthand accounts written by hospice patients of Saunders's. These personalized commentaries were very emotionally moving and provided insight into what the patients were feeling.


**Secondary Sources**

This source provided me with some helpful information about Cicely Saunders International.

This source helped explain Wald’s work and informed about how she went on to lead changes in American hospice and help prisoners with access to hospice care.

This source helped me understand how the most common causes of death have changed over the years.

This source was focused on the visits Saunders made to the US. It helped me understand the significance of the visits she made and how important they were in starting the hospice movement in the US. This also was the source of a great quote by Saunders when she gave her speech at Yale.

*Consider the Conversation.* Produced by Terry Kaldhusdal, 2011.
This source gave me many different professional views on end of life care and offered many pieces of information on end of life care.

This source provided me with a good synopsis of how Saunders went on to form hospice and also was a source for a good quote.

This source gave me a different and insightful perspective on Saunders and her accomplishments. It was biographical information written by her brother.
This source gave me a good overall biography of Saunders's life. It also reflected on how she came to focus on hospice and why she started to work on helping dying patients.

This source provided a good look at Saunders’s life in detail. It also explained some of her key achievements relating to hospice.

This source told the story of Terri Schiavo. It provided a real example of the tragic effects of futile and unnatural prolongation of life with live support equipment.

This source helped me understand some of the reasons that life expectancy has gone up and how antibiotics have advanced in the past century.

This source demonstrated how medical procedures are very costly. It also showed that hospital care is very expensive.

This source provided information on how hospice care was created and some of the factors which contributed to the creation of hospice.

This source contributed good information about statistics regarding hospice care in the U.S.

This source helped me better understand the different end of life care options. It also provided insight into the cost.

This source helped me understand Wald’s life better and included good details on her achievements in the advancement of hospice care.


This source provided information on Wald. It included insight into her life and achievements.


This source helped me better understand hospice care. It enlightened me on how great the need is for hospice care in today's society. It also touched on the barriers of access to and development of palliative care and how to overcome these barriers.


This source demonstrated how the hospice movement has been evolving. Included details on average length of stay in hospice as well as information about access to hospice care. It had some good graphs demonstrating these trends.


This source contributed to my understanding of how causes of death have changed.


This source provided good information on the development of medicines for anesthesia.


This source helped me better understand the history of dying and the large impact of St. Christopher’s Hospice on so many people.


This source provided insight into the evolution of hospice care. This source is important to my paper because it gave me some good information about how the hospice movement evolved and how the first hospice center was started in the U.S.
This article provided good information on how Saunders extensively pioneered hospice and palliative care.

This source informed me of how hospice care started and how it has evolved. It also included a good timeline with specific years and that showed how hospice has evolved.

This source included good information through a timeline that demonstrated how medicine has changed and improved health and life expectancy.

"Hospice Care Cost/Financing Options." *SeniorCare.ORG*, www.seniorcare.org/hospice-care/hospice-care-cost/. This source provided good information about hospice care costs and resources. It also included good insight into the costs of ICU care.

This source contributed some really stunning facts and statistics about hospice care and end of life care.

This source helped me learn about current hospice statistics. It also contributed to my knowledge on how hospice can continue to improve.

This source explained to me what an almoner was. It also gave me key details that show how an almoner relates to a social worker today

This source had good information on the International Association for Hospice and Palliative Care including information on its founders it and its purpose.
"International Association of Hospice and Palliative Care." National Hospice and Palliative Care Organization, www.nhpco.org/link/international-association-hospice-and-palliative-care. Accessed 5 Feb. 2019. This source informed me about the International Association of Hospice and Palliative Care and what their goals and initiatives for increasing accessibility to hospice care.


J Hosp Palliat Nurs. 2011 Nov-Dec; 13(6): S35–S43.doi: 10.1097/NJH.0b013e3182331160 This source helped me understand how hospice evolved in the US. It provided insight into the suffering which can occur when incurable death is extended.


Kiernan, Stephen P. Interview. 15 Jan. 2019. This interview was an hour and a half in length. It included information on the history of dying, and of hospice care. It also included an insightful firsthand account of the struggles of losing two parents amidst the influences of modern medical technology. It gave me a deep appreciation for the significance and value of the modern hospice movement for humanity.

---. Last Rights. New York, St. Martin's Press, 2006. This book provided many statistics and facts about the end of life care in hospitals and hospices. It also included many stories that helped me better realize the importance of hospice care.

"Mechanical Ventilators." Science Museum Brought to Life Exploring the History of Medicine, broughttolife.scenecemuseum.org.uk/broughttolife/techniques/mechanicalventilators. This article contained information on the history of ventilators. It also included a photograph that helped me appreciate what life support machines looked like.

"National Hospice and Palliative Care Organization." National Hospice and Palliative Care Organization, www.nhpco.org/nhpco-0. Accessed 5 Feb. 2019. This resource gave me information on the mission, goals, and history of the National Hospice and Palliative Care Organization.


"A Profile of Death and Dying in America." National Center for Biotechnology Information, 1997, www.ncbi.nlm.nih.gov/books/NBK233601/. Accessed 3 Feb. 2019. This source informed me that because technology has advanced so much, dying in America has changed. It helped me understand that when death is prolonged by technology, important opportunities for living and interacting with loved ones while dying are lost.


This source shared the history of hospice as well as expectations that it is going to continue to evolve. It also led me to some other sources and provided a short timeline on modern hospice and some of the things that have influenced it as it has developed.

This source informed me of recent worldwide causes of death and how they differed from the U.S.

This source gave me a better understanding of Terri Schiavo and Karen Ann Quinlan. It also helped me better understand how these incidents occurred.

This source shared similarities and differences between hospice and palliative care which are often used interchangeably.

This source explained to me the dying process in more detail. It also helped me better understand how dying is very different with every person and therefore must be individualized for each person.

This resource contributed powerful information about where Americans die and how that compares to where they would prefer to die.