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OCCUPATIONAL THERAPY WITHIN PALLIATIVE CARE

EASTERN KENTUCKY UNIVERSITY

Analyzing the Benefits of Occupational Therapy within Palliative Care for  
Patients with Cancer: A Systematic Review

Honor's Thesis  
Submitted  
in Partial Fulfillment  
of the  
Requirements of HON 420  
Spring 2018

By

Erin Pyle

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Analyzing the Benefits of Occupational Therapy within Palliative  
Care for Patients with Cancer: A Systematic Review

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Palliative care is a holistic approach to care for individuals with serious or terminal illnesses. Palliative care has been shown to be especially beneficial for individuals with a cancer diagnosis. With the incidence of cancer in the United States on the rise, palliative care is a relevant and valuable service. The team that delivers palliative care is multidisciplinary and includes a variety of healthcare providers as well as professionals for emotional and spiritual support. Occupational therapy is beginning to be included within this team. Occupational therapy has also been shown to improve performance and function in individuals with cancer. This systematic review aims to investigate the effectiveness of including occupational therapy within palliative care for patients with cancer.

*Key words and phrases:* palliative care, cancer, occupational therapy, systematic review, United States

## Table of Contents

|                                       |    |
|---------------------------------------|----|
| Acknowledgements.....                 | iv |
| Background and Problem Statement..... | 1  |
| Statement of Purpose.....             | 2  |
| Research Question.....                | 3  |
| Definition of Terms.....              | 3  |
| Assumptions.....                      | 4  |
| Literature Review.....                | 6  |
| Methods.....                          | 16 |
| Results.....                          | 23 |
| Themes.....                           | 23 |
| Discussion.....                       | 29 |
| Limitations.....                      | 31 |
| Implications and Conclusion.....      | 31 |
| References.....                       | 33 |

List of Figures

Figure 1 .....19

List of Tables

Table 1 .....18

Table 2 .....20

Table 3 .....28

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### Background and Problem Statement

Palliative care is an essential healthcare service for many people with serious or terminal illnesses. Currently, in the United States, there are nearly 90 million people living with serious disease, and that number of people is estimated to grow due to advances in medical technology and an increase in average lifespan (Center to Advance Palliative Care, 2018). Palliative care is a holistic and client-centered approach to care that focuses on the physical, spiritual, and psychological wants and needs of the individual as well their family. One of the main goals of palliative care is to increase quality of life for the individual at the end of life. This is often through the use of medication to manage symptoms and increase comfort, counseling to cope with death, and open communication and coordination between all healthcare providers (Center to Advance Palliative Care, 2018). Quality of life can be described as a subjective measure of how satisfied an individual is with their life. Since palliative care is a holistic method of care, it is provided by a multidisciplinary team that includes physicians, nurses, dietitians, social workers, chaplains, and more.

Palliative care differs from hospice because it can be incorporated with curative treatments; hospice is recommended when individuals are given less than six months to live by their physicians. For this reason, palliative care is a valuable service for individuals with a cancer diagnosis. The palliative care treatments can be given simultaneously with curative treatments in an effort to maximize quality of life for the individual. Cancer is an epidemic in the United States, with an approximate 1,735,350 being newly diagnosed this year (Seigel, Miller, & Jemal, 2018). In Kentucky, an estimated 25,990 individuals are being diagnosed with cancer and 10,590 individuals are dying due to cancer (Seigel et al., 2018). In all of these cases, palliative care is a relevant and often necessary method of care. Palliative care has been proven to be beneficial for

individuals with cancer because it reduces distressing physical and psychological symptoms (Howie & Peppercorn, 2013). Early intervention with palliative care for individuals with cancer has also been shown to be effective in improving outcomes, quality of life, and potentially survival (Howie & Peppercorn, 2013). Overall, it is clear that palliative care has a vast, positive impact on the individual receiving care and their family.

Occupational therapy is also an evidence-based practice that has been proven effective for many individuals with an array of illnesses (Smith-Gabai & Holm, 2017). The ultimate goal of occupational therapy is to increase an individual's participation in the activities or occupations that they find valuable with adaptations if necessary (AOTA, 2014). In the context of oncology, occupational therapy is a valuable method of care for individuals with cancer. The purpose of occupational therapy in oncology is to improve function, maintain independence, promote wellness, reduce cognitive deficits due to chemotherapy, and improve overall quality of life (Longpre & Newman, 2011). Cancer is an epidemic in the United States and results in significant declines in function and quality of life. Both occupational therapy and palliative care have been proven to improve function and life quality for patients with a variety of conditions. However, there is not a compilation of literature that reveals the effectiveness of incorporating occupational therapy in palliative care.

#### Statement of Purpose

With the continuing rise of the incidence of cancer in the United States, care for this population is becoming increasingly important. Palliative care has been shown to improve quality of life for those with a cancer diagnosis. Occupational therapy intervention and services have also been shown to be effective in improving function and quality of life for individuals with cancer. However, there is little evidence showing the effectiveness of the combination of



these services for patients with cancer. This systematic review aims to analyze available literature to investigate the effectiveness of occupational therapy within palliative care for patients with cancer.

#### Research Question

What is the evidence for the effectiveness of incorporating occupational therapy within palliative care for patients with cancer?

#### Thesis

The inclusion of occupational therapy in holistic palliative care will result in increased quality of life at the end of life for patients with cancer.

#### Definition of Terms

**Cancer:** a collection of related diseases involving the abnormal division of cells (National Cancer Institution, 2015)

**Hospice:** “a cluster of comprehensive services for terminally ill persons with a medically determined life expectancy of 6 months or less” (Shi & Singh, 2019, p. 294)

**Meta-analysis:** a quantitative, formal, epidemiological study design used to systematically assess the results of previous research to derive conclusions about that body of literature; typically, the study is based on randomized, controlled clinical trials but may include other research types (Haidich, 2010)

**Oncology:** “a branch of medicine concerned with the prevention, diagnosis, treatment, and study of cancer” (Merriam-Webster, 2018)

**Occupation:** “activities...of everyday life, named, organized, and given value and meaning by individuals in a culture...everything people do to occupy themselves...enjoying life...and contributing to the social and economic fabric of their communities” (AOTA, 2014, p. S5)

**Occupational therapy:** “therapy based on engagement in meaningful activities of daily life (such as self-care skills, education, or social interaction) especially to enable or encourage participation in such activities despite impairments or limitations in physical or mental functioning” (Merriam-Webster, 2018)

**Occupational therapy intervention:** involves an occupational therapist and the therapeutic use of daily activities, or an occupation (American Occupational Therapy Association, 2018); “focuses on creating or facilitating opportunities in occupations that lead to participation in desired life situations” (AOTA, 2014, p. S1)

**Palliative care:** a method of care for individuals with terminal illness; focus is on relief of symptoms, comfort, and improving quality of life for the individual and their family; can be utilized at any point during a serious illness (Center to Advance Palliative Care, 2018)

**Quality of life:** “the standard health, comfort, and happiness experienced by an individual or group” (Oxford Dictionary, 2018)

**Systematic review:** a thorough and rigorous analysis of available literature on a particular subject which provides a high level of evidence in order to inform healthcare recommendations (Cochrane Library, 2018)

### Assumptions

There were many assumptions made prior to conducting the systematic review. The author is an occupational science student and an advocate for occupational therapy, therefore the author assumed that occupational therapy would have a positive impact on the individuals in the studies. The author is also an advocate for palliative care, so the author is assuming that palliative care will have a positive impact as well. The author also assumed that the individuals would value palliative care and the occupational therapy services. Lastly, the author is assuming

that the information and results provided in the articles that were analyzed as part of this review were accurate.

## Literature Review

### **Palliative Care**

Palliative care is an essential aspect of health care for individuals with terminal illnesses. The focus of palliative care is providing relief from symptoms and stress of the illness as well as providing resources and care for the family of the individual (Center to Advance Palliative Care, 2018). This multifaceted approach to palliative care has been shown to have a profound impact on the patient and family of the patient since the goal is to improve quality of life for both (Spilsbury et al., 2017). The team that delivers palliative care is multidisciplinary and includes doctors, nurses, registered dietitians, pharmacists, chaplains, psychologists, and social workers (National Cancer Institute, 2017). With this diverse team, a range of issues are addressed pertaining to the physical and emotional effects of cancer like physical symptoms, emotional stress and coping, spiritual guidance, caregiver needs, and practical needs. Data collected in 2014 revealed that 1.66 million patients received hospice or palliative care services, and the average length of service was 71.3 days (Shi & Singh, 2019). Data also showed that 83.9% of patients were above 65 years of age, majority female (53.7%), and mostly white (76%); 36.6% of the patients were diagnosed with cancer (Shi & Singh, 2019).

Death is inevitable, but a focus on comfort in the end days is beneficial for patients of all ages and illnesses, specifically individuals with cancer. Palliative care has been shown to be most beneficial when integrated soon after a cancer diagnosis (National Cancer Institute, 2017). Palliative care can be provided at any point on the cancer care continuum. Typically, palliative care is for patients with a terminal illness with less than six months to live (Shi & Singh, 2019). When describing palliative care, it is important to note that palliative care is often used interchangeably with hospice, but there is a key difference in the utilization between the two

services. Palliative care is an umbrella term that hospice falls within. Palliative care can be utilized at any point for a patient with terminal cancer or a terminal illness (National Cancer Institute, 2017). On the contrary, hospice begins when the curative treatment of the disease or cancer is no longer the focus or goal of care (National Cancer Institute, 2017). Due to the versatility and benefits of palliative care, it is a rapidly growing area of medicine in the United States (Hughes & Smith, 2014). Palliative care in the future includes more penetration into other fields, indicating that palliative care will continue to have an impact on the overall healthcare system in the United States.

The population impacted by palliative care is vast and diverse because it includes individuals of all ages with serious, often terminal conditions. There are approximately 90 million Americans living with serious illness, and this number is expected to grow due to advances in medical care and an aging population (Center to Advance Palliative Care, 2014). The most common diagnoses with palliative care are heart disease, cancer, stroke, diabetes, renal disease, Parkinson's, and Alzheimer's disease (Center to Advance Palliative Care, 2014). According to the Center to Advance Palliative Care (2014), there are 6 million individuals in the United States with conditions that could benefit from palliative care. Because of the high incidence of cancer in the United States, cancer patients make up a large portion of the population needing palliative care. There are states where palliative care is more common—states where there is more access to care. According to the report card created by Center to Advance Palliative Care, three states—New Hampshire, Vermont, and Montana—received a score of 100. Overall, there were 17 states were rated an A, which is above the national average. The Center to Advance Palliative Care (2018) indicated that the barriers to palliative care access in low scoring states are workforce, research, and payment models linked to quality measures.

## **Cancer**

Cancer, according to the National Cancer Institute (2015), is a collection of related diseases, where some of the body cells begin to divide abnormally and rapidly forming a growth called tumor. Tumors can be either malignant or benign; malignant tumors are cancerous and can originate anywhere in the body (National Cancer Institute, 2015). Cancer is the second leading cause of death worldwide, responsible for 8.8 million deaths in 2015 (World Health Organization, 2018). Data presented by the World Health Organization (2018) revealed that lung, prostate, colorectal, stomach, and liver cancer are most common in men, while breast, lung, cervix, and stomach cancer are most common among women. Treatment and management of cancer can include surgery, medicine, radiotherapy, palliative care and many other interventions (World Health Organization, 2018).

There are many factors, both environmental and genetic, that are responsible for causing cancer. Exposure to chemicals, radiation, air pollution, and carcinogens are examples of extrinsic factors contributing to cancer diagnoses (Smith-Gabai & Holm, 2017). Internal factors include age, heredity, immune system competence, and metabolic abnormalities (Smith-Gabai & Holm, 2017). Within oncology, there is also a process called staging and grading, which determine the extent, spread, and prognosis of cancer (Smith-Gabai & Holm, 2017). Staging also aids physicians in creating a treatment plan (Radomski & Latham, 2014). The staging process generally involves the TNM method where the tumor size (T) is identified as well as lymph node involvement (N) and spread of cancer (M) (Radomski & Latham, 2014). Tumor size (T) is ranked on a scale of 1-4, describing the size and invasion of the tumor; the higher the number, the larger and more invasive the tumor (Smith-Gabai & Holm, 2017). Therefore, a stage 4 tumor is considered the most aggressive and fatal (Smith-Gabai & Holm, 2014).

## **Occupational Therapy**

Occupational therapy, in simplest terms, is a service that helps individuals do the things that they want to do and have to do through the therapeutic use of occupation (American Occupational Therapy Association, 2018). Occupations are everyday activities—everything from going to the movies to taking a shower. Occupational therapy is a holistic service, meaning that adaptations to an environment are made to benefit the individual receiving therapy and the individual is an integral part of the therapy team (American Occupational Therapy Association, 2018). An emphasis is often placed on the valued occupations of the client, which are the daily activities that the client finds meaningful, pleasurable, or necessary for their day-to-day life.

## **Cancer and Occupational Therapy**

Occupational therapy can improve performance for all individuals, either through remediation or adaptation of valued occupations (AOTA, 2014). Occupational therapy often has a role in the treatment of individuals with cancer. According to Smith-Gabai and Holm (2017), occupational therapy is a valuable service for patients with cancer because occupational therapy promotes wellness, improves functional outcomes, addresses cancer related symptoms, and addresses psychosocial changes. More specifically, occupational therapists can improve arm function in individuals who have had cancer related surgeries through the use of exercise and activity to improve range of motion (ROM), strength, and coordination (Radomski & Latham, 2014). Occupational therapists can also address fatigue by educating individuals about energy conservation techniques (Radomski & Latham, 2014). Occupational therapists have also been shown to reduce cognitive deficits that are a result of “chemo brain” in many individuals with cancer (Radomski & Latham, 2014). Chemo brain can be described as a mild cognitive impairment that individuals experience after chemotherapy (Radomski & Latham, 2014). The

areas typically impacted are attention, learning, executive function, and information processing speed (Radomski & Latham, 2014).

### **Cancer and Palliative Care**

Palliative care is most commonly associated with oncology. There are studies that indicate that starting palliative care following a cancer diagnosis is most beneficial. Palliative care in conjunction with other cancer treatments is ideal (National Cancer Institute, 2017). There are specific palliative care plans for patients with cancer, like the “Cancer Home-Life Intervention.” This intervention was shown to provide better support for patients with advanced cancer in their daily lives at home (Brandt et al., 2016). According to the Center to Advance Palliative Care (2014), there are 6 million individuals in the United States with conditions that could benefit from palliative care. The diagnoses among these individuals are diverse, however, a significant portion likely have cancer due to the high incidence of cancer in the United States. According to Shi and Singh (2019), more than half of individuals receiving palliative care were diagnosed with cancer upon admission. Palliative care specifically aims to reduce distressing symptoms for individuals with cancer. These symptoms could be physical, emotional, or spiritual, and the team delivery care is prepared to assist both the individual and their family (Center to Advance Palliative Care, 2018).

With improvements in medical care and technology, the life expectancy of Americans has been lengthened to 78.74 years (World Bank, 2015). The “baby boomer” generation is expected to live longer than previous generations, and they are in need of medical attention as they age (Teno et al., 2015). Aging typically brings a host of complications, and cancer is unfortunately an epidemic responsible for the most deaths in the United States (Siegel, Miller, & Jemal, 2017). Siegel, Miller, and Jemal (2017) combined data from multiple mortality databases



in the United States between 1930 and 2014 to create an estimate of new cancer cases and deaths in 2017. According to this prospective estimate, 1,735,350 individuals will be diagnosed with cancer in 2018, and 609,640, about one-third, of these individuals will die from the cancer diagnosis (Siegel, Miller, & Jemal, 2018).

### **Cancer and Palliative Care in Kentucky**

Data, specific to Kentucky, was collected to create estimates of cancer diagnoses in the state (Siegel, Miller & Jemal, 2018). The estimated number of individuals diagnosed with cancer in Kentucky within the year is 25,990 cases; the estimated number of deaths due to cancer in 2017 in Kentucky is 10,590 (Siegel et al., 2017). In addition, data was collected per state in 2015, recording the access to palliative care in United States' hospitals. The report tracks the growth of palliative care programs across the nation and highlights areas where gaps in access occur (Center to Advance Palliative Care, 2018). The data was collected and rated in a report card fashion, each state receiving a score that aligned with letter grades A-F. Kentucky received a score of 53.1, which is a C (Center to Advance Palliative Care, 2018). The criteria that each state was rated on was the number of large hospitals in the state in comparison to the number that have palliative care programs, revealing the access to palliative care (Dumanovsky et al., 2016). While Kentucky is not the lowest ranking state, it is below the nation's average score, which is a B. This is likely due to the geographic region that Kentucky is included in—East South Central, United States. The states in this region had some of the lowest rates of access to palliative care, which is likely due to the rural areas and lower socioeconomic status (Dumanovsky et al., 2016). The number of hospitals offering palliative care in Kentucky needs to increase in order to attain parity with the rest of the nation.

### **Palliative Care and Occupational Therapy**

Palliative care applies to occupational therapy because the values of each service align. According to the American Occupational Therapy Association Code of Ethics, the values of occupational therapy include altruism, equality, freedom, justice, dignity, truth, and prudence (American Occupational Therapy Association, 2015). One of the main goals of palliative care is to improve the quality of life of patients, helping individuals in need gain the strength to carry on with daily life (Center to Advance Palliative Care, 2018). These goals are similar and overlap in many ways. According to Costa and Othero (2012), occupational therapy and palliative are both client-centered services by nature.

Occupational therapy has been involved in the delivery of palliative and hospice services since the entry of the concept in the concept in the 1980s in the United States (Mizzi, 1984). Mizzi (1984) provided an interesting prospective on the role of occupational therapy in hospice, writing that occupational therapists should emphasize that “the dying are still living persons, with feeling, abilities, hopes, and dreams.” With this holistic knowledge of a person, Mizzi (1984) urges that occupational goals should be in accordance with the roles, needs, and desires of the patient in order to enhance quality of life. This goal aligns closely with the Center to Advance Palliative Care’s (2018) description—“The team will help you gain the strength to carry on with daily life.” As an occupational therapist, clients may be referred to OT services following their diagnosis of a terminal illness. Occupational therapists should have knowledge of palliative care so that they are able to help the healthcare team, client, and client’s family make the best and most informed decision. Occupational therapy would be a beneficial service to include under palliative care because the values and goals align well. A patient with a terminal

illness might need help maintaining their occupational identity, roles, habits, and routines (Costa & Othero, 2012).

A recent article demonstrated how palliative care could be included in the Model of Human Occupation, or MOHO (Costa & Othero, 2012). The Model of Human Occupation is an important model within the field and practice of occupational therapy because it observes the motivations, patterns, and performances of occupations within a context and environment (Costa & Othero, 2012). This systems-based theory looks at the entire individual, and it is client-centered, meaning that the wants and needs of the individual receiving services are a key factor. For these reasons, applying the Model of Human Occupation to palliative care is beneficial to the terminally ill patient because they are able to maximize their participation in valued occupations and in turn, maximize their quality of life (Costa & Othero, 2012). The main goal of palliative care is to improve the quality of life of patients, helping individuals in need gain the strength to carry on with daily life (Center to Advance Palliative Care, 2018). The goals of occupational therapy are in alignment with those of palliative care.

### **Palliative Care in the Context of Current U.S. Healthcare**

Palliative care is relevant to current healthcare policies because of insurance coverage needed to support these services. The information used to qualify patients for palliative care sometimes varies by state (National Cancer Institute, 2017). Palliative care has had a complex history with policymakers, making it a popular topic of discussion recently (Mor, 2016). The concept of palliative care emerged in the United States in the 1970s, and it has been a topic of discussion since (Shi & Singh, 2019; Mor, 2016). In the 1990s, Congress passed the Patient Self Determination Act, which required hospitals to ask patients about their end-of-life preferences. The goal of this act was to decrease the amount of “undesired and unplanned intensive health

care utilization” at the end of patients lives (Mor, 2016). Palliative care became a part of this conversation because it is an option of end-of-life care that minimizes cost and maximizes quality of life (Hughes & Smith, 2014). Palliative care has recently reentered healthcare policy discussion because of the growth of the Medicare hospice benefit (Mor, 2016). Another common problem with the delivery of palliative care is that there is not a standard way to evaluate the effectiveness (Burstin & Johnson, 2017). Between private and public coverage, there has not been a consensus made regarding quality of care (Burstin & Johnson, 2017). The United States is currently in a transition phase, beginning to shift payment for value rather than volume, emphasizing a value-based healthcare system as well as a person-centric approach (Burstin & Johnson, 2017). According to Burstin and Johnson (2017), palliative care is leading the nation in this shift.

Palliative care will have implications on healthcare service delivery because it will impact the cost of healthcare. However, palliative care has been shown to be more cost-effective for patients instead of multiple emergency hospital stays (Burstin & Johnson, 2017). The use of palliative care should be increased because of the obvious benefits for the patient and loved ones of the patient. The consequence of increasing the use of palliative care for cancer patients would be a more cost-effective plan of treatment for patients. Community-based palliative care was shown to reduce acute care health services, which tend to be most costly (Spilsbury et al., 2017). Another consequence would be patients receiving quality care that improves their quality of life, both in the beginning phases of diagnosis and terminal phases nearing death. The approach for cancer patients includes managing physical symptoms, coping emotionally, spiritual guidance, meeting caregiver needs, and meeting practical needs (National Cancer Institute, 2017). This

holistic approach is also client-centered, with the goal of providing the best care for the patient and their family.

## Methods

A systematic review was conducted to investigate and answer the research question. A systematic review is a rigorous analysis of existing literature. According to Cochrane Library (2018), a systematic review “summarizes the results of available healthcare studies...and provides a high level of evidence.” It is important to note that systematic reviews depend largely on the number and quality of studies available (Cochrane Library, 2018). The studies available for this particular review were diverse therefore a meta-analysis was not possible. Meta-analyses are similar to systematic reviews, however they pool the numerical data from studies to investigate the effectiveness of interventions (Cochrane Library, 2018). Systematic reviews are used often in healthcare to inform recommendations for services (Cochrane Library, 2018).

The author performed a comprehensive search of the literature using an electronic search strategy. Table 1 shows the combinations of key terms used to search the databases. The databases utilized were Medline, Academic Search Complete, and PubMed. A limitation of the process would be the exclusion of research articles written in languages other than English. Figure 1 on page 24 shows the process the author used to narrow the search. The author started each search with an individual query of the following terms or phrases: “cancer,” “palliative care OR end of life care OR terminal care OR dying,” and “occupational therapy.” The results of each of these searches were too broad. The author began to combine search terms and phrases in order to narrow the search for appropriate research articles related to the study question.

The ending combination was all three search terms or phrases, which yielded the most specific and narrowed results. There were 36 hits with these search terms through the database Academic Search Complete, 48 hits through the database Medline, and 152 hits through the database PubMed. An illustration of this process can be seen on page 24, Figure 1. The author

then read the titles of each article yielded through the search. Based on title, 32 of 36 articles were eliminated because they did not meet the inclusion criteria for this systematic review, as described in the next section. The author then read the abstracts of each article and disregarded 1 more article that did not meet the qualifications. The same process was followed using the results from Medline, and 43 of the 48 articles yielded by the search terms were removed based on title. Further, 3 articles were removed because they were duplicates of the Academic Search Complete results. The author read the abstracts of the remaining 2 articles and both qualified. The same process was followed using the results of PubMed, and 147 out of 152 articles were removed based on title. The remaining 5 articles were all duplicates from the previous two database searches. The author also utilized a hand search of the references from each article included. Based on title, no articles were chosen using the hand search method for the systematic review.

### **Inclusion Criteria**

The inclusion criteria for the systematic review was broad because there was a lack of published literature in the area. The studies had to be written in or translated to the English language, so the author could read and understand them. The other qualifications included involving patients who have a cancer diagnosis who are also receiving palliative care. The study also had to have utilized an occupational therapy intervention in some capacity. The articles had to be peer reviewed and published in a scientific journal. The number of participants and the method of data collection were not considered to be criteria due to the lack of studies conducted and published in this area.

Table 1. Results of the Comprehensive Search of Literature Using an Electronic Search Strategy

| Search term   | Academic Search Complete | Medline   | PubMed    |
|---|--------------------------|-----------|-----------|
| S1: Cancer  | 1,040,143                | 1,767,191 | 3,637,797 |
| S2: Palliative care or end of life care or terminal care or dying | 72,372                   | 106,716   | 142,504   |
| S3: Occupational therapy  | 15,041                   | 24,967    | 45,810    |
| S1 and S2   | 16,857                   | 29,678    | 125,810   |
| S2 and S3   | 358                      | 452       | 2,779     |
| S1 and S3   | 149                      | 188       | 121,174   |
| S1 and S2 and S3  | 36                       | 48        | 152       |

### Data Extraction

The data extracted included title and nation of origin, aim of study, service setting, sample, methodology, outcome measured, results/descriptive themes, and key findings. The author recorded each component in a table in Microsoft Word. The table can be seen on page 25, Table 2. Studies included in the review yielded qualitative and quantitative results. New descriptive themes emerged through the author's analysis of the combined articles. Due to diversity in study type, methodology, and sample size, meta-analysis was not possible.



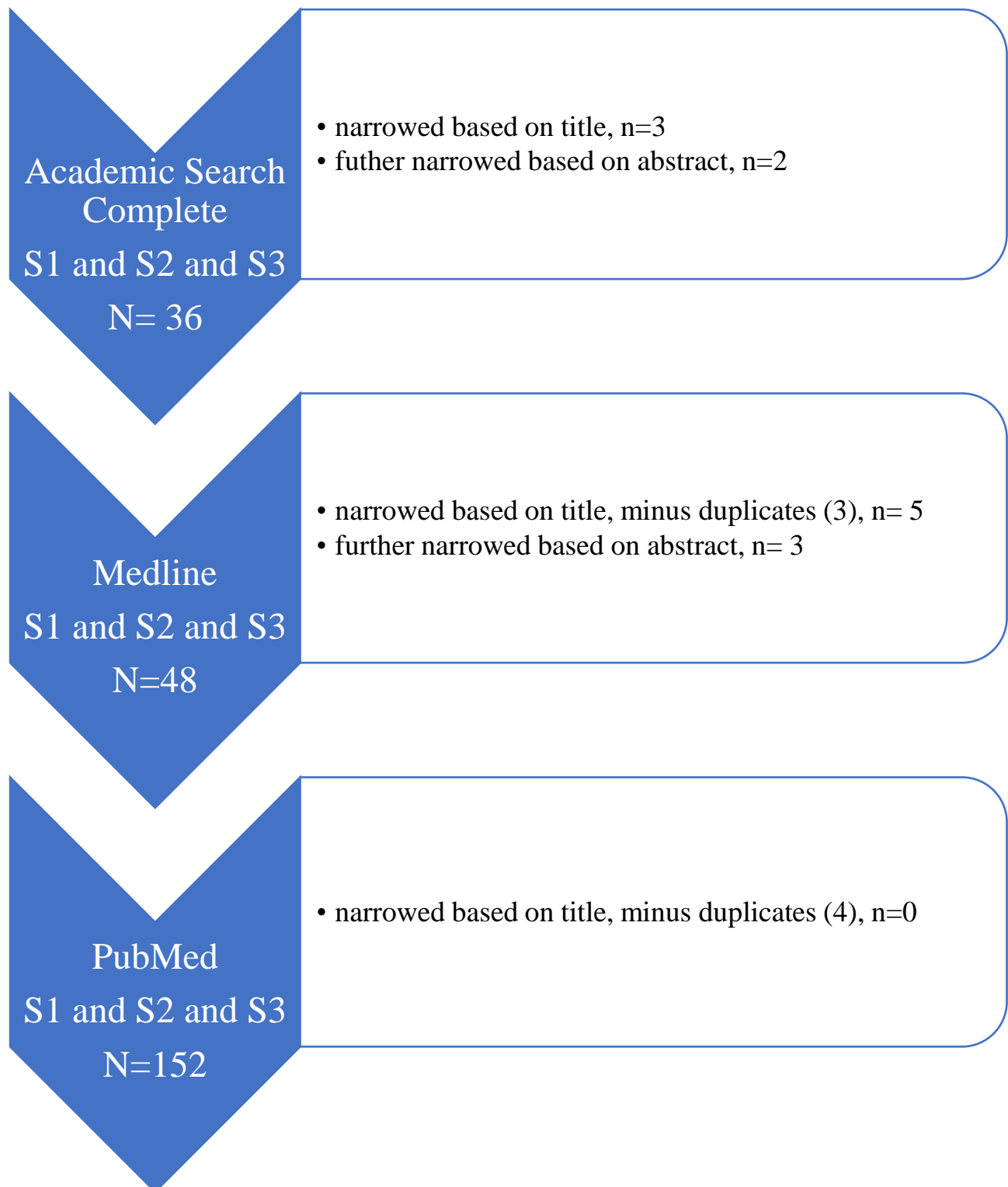


Figure 1. Flow chart illustrating the method of gathering articles for the systematic review.

| <b>Title and nation of origin</b>                            | <b>Aim of study</b>  | <b>Service setting</b>        | <b>Sample</b>  | <b>Methodology</b>   | <b>Outcome measured</b>  | <b>Results/ Descriptive themes</b>  | <b>Key findings</b>   |
|--|--|-------------------------------|--|--|--|---|---|
| Kasven-Gonzalez, Souverain, & Maile<br>2009<br>United States | To investigate the value and effectiveness of collaboration between the occupational therapist, physical therapist, and individual with cancer in an effort to improve quality of life at the end of life. | Hospital, Intensive Care Unit | 23-year-old female with osteosarcoma and leukemia  | Case report  | Impact that physical activity through OT and PT interventions had on the patient's quality of life | Themes: Verbal appreciation, positive atmosphere promotes improved quality of life, motivation for valued occupations, relief from distressing symptoms | Palliative care patients may benefit from occupational therapy and physical therapy intervention because rehabilitation specialists are skilled at working with patients to set realistic and meaningful functional goals |
| Kealey & McIntyre<br>2004<br>United Kingdom                  | To evaluate the home occupational therapy service for individuals in the palliative stage of cancer from the patient perspective and the   | The homes of the patients     | Purposive sample of 30 patients in the palliative stage of cancer who had been referred to domiciliary occupational therapy services | Descriptive study; Structured interviews using pre-designed questionnaires with close-ended and open-ended questions | Satisfaction and accessibility to occupational therapy services within domiciliary palliative care | Qualitative: Patient, family, and medical staff reported positive results<br><br>Quantitative: Likert scale 0-4: majority of patients and               | Qualitative and quantitative data collected indicated high levels of client and care taker satisfaction with communication and with accessibility to the domiciliary occupational therapy service.                        |

|                                       |  |   |   |  |   |   |  |
|---------------------------------------|--|---|---|--|---|---|--|
|                                       | perspective of caregivers.   |   |   |  |   | care givers rated 4, followed by 3 for satisfaction with OT services  |  |
| Eriksson & Lindberg<br>2016<br>Sweden | To describe how individuals receiving palliative care in a hospital relate to occupation and the meaning that it offers their life.                          | Hospital, inpatient palliative care   | Purposive sample of 8 patients with various cancer diagnoses                                | Narrative and thematic interview that was recorded and transcribed   | Patients reported of a sense of loss of their role as a person, lack of control, and lack of participation in life.   | Themes: Loss of occupation, living with disease, unable to control existence, controlling social contacts   | Occupation is important to patients receiving palliative care so that they can have a sense of self, know their role, and have a sense of control.             |
| Sakaguchi & Okamura<br>2014<br>Japan  | To examine the narratives that emerged from participating in life narrative collage activity with elderly individuals with cancer receiving palliative care. | Varied—homes of patients receiving palliative care, palliative care unit of a rehabilitation hospital, or in a clinic for palliative care | Purposive sample of 11 (7 male, 4 female) elderly cancer patients receiving palliative care | Participants completed an evaluation pre-intervention; a life-review interview was given; participants were guided through making a collage with old photographs; participants | Evaluations: Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp), The Hospital Anxiety and Depression Scale (HADS), and the Self-Efficacy | Quantitative: Statistically significant changes: Hospital Anxiety and Depression Scale (HADS): anxiety (p=0.034), depression (p=0.042), and overall (p=0.026) | A collage activity based on a life review may be effective for improving spiritual well-being, mitigating anxiety and depression, and improving self-efficacy. |

|                                  |  |                          |  |  |   |  |   |
|----------------------------------|--|--------------------------|--|--|---|--|---|
|                                  |  |                          |  | completed the same evaluation post-intervention  | Scale for Terminal Cancer (SESTC)   | - Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp): meaning of life and peace (p=0.004), faith (p=0.001), and overall (p=0.002) |   |
| La Cour et al.<br>2007<br>Sweden | To investigate the impact engaging in creative activities has on individuals with cancer in palliative occupational therapy. | Palliative care facility | Purposive sample of 8 women (age 41-74) with cancer, receiving palliative care with an interest in arts and crafts | Phenomenological research approach; total of 16 conversational interviews conducted among the 8 participants who were participating in creative activities during weekly during their stay | The themes emerging from the interviews were how the creative activities eased life in proximity to death and offered an alternative way to deal with life. | Easing life before death, alternative ways to deal with life   | Engagement in a creative activity in the form of crafts may be a significant tool for patients receiving palliative care for finding ways to handle challenges in ongoing life. |

## Results

After extracting data, articles were grouped based on the types of research conducted. The author created a qualitative group, consisting of four articles: Kasven-Gonzalez et al. (2009), Kealey and McIntyre (2004), Eriksson and Lindberg (2016), and La Cour et al. (2007). The quantitative group included Sakaguchi and Okamura (2014) and Kealey and McIntyre (2004). To synthesize the results, the author analyzed the common themes between the qualitative studies. The results of quantitative studies were also used as further evidence to support these themes. The process of analyzing, separating, and creating new themes can be seen on page 33, Table 3. The common themes developed by the author include improving life at the end of life, coping at the end of life, engaging in valued occupations at the end of life, and interacting with loved ones and healthcare providers at the end of life.

## Themes

**Improving life at the end of life.** This theme was found in Kasven-Gonzalez (2009) and La Cour et al. (2007). A common theme seen in Kasven-Gonzalez (2009) that relates to improving life at the end of life was relief from distressing symptoms. This study was a case report focused on a young individual with cancer who was receiving palliative care as well as rehabilitative services, including physical and occupational therapy. The physical therapist and occupational therapist worked together with the individual to create goals that provide relief from distressing symptoms. The article states that participating in physical activity and being able to perform activities of daily living (ADLs) has an impact on reducing distressing symptoms. The theme of improving life is evident because the interventions provided for the client minimized distressing symptoms therefore improving life at the end of life.

The theme of improving life at the end of life was also seen in La Cour et al. (2007). A theme drawn from this study that relates to improving life was easing life before death. This qualitative research was collected from individuals with cancer who were engaging in creative activities in occupational therapy at a palliative care facility. This theme emerged from a theme developed by the researchers, which was “easing life in proximity to death” (La Cour et al., 2007). The theme arose through interviews with participants in the study who spoke about the positive focus that the creative activity brought to their life despite their health circumstances (La Cour et al., 2007). This theme relates to improving life at the end of life because the participants reported feelings of hope and joy while participating in the creative activities. The participants were able to shift their focus from the negative aspects of cancer to the positive aspects of engaging in creative activities, therefore enhancing quality of life in the midst of terminal illness.

The results of the quantitative data collected in Kealey and McIntyre (2004) also support the theme of improving life at the end of life. The authors distributed a Likert scale questionnaire to the participants and their caretakers. The questionnaire was focused on overall satisfaction that participants felt toward the occupational therapy interventions provided. The scale was 1-4, with 1 being the lowest level of satisfaction and 4 being the highest level of satisfaction. The occupational therapy interventions included “equipment, adaptations, techniques, range movement and muscle/strength, advice recondition [repair], fatigue management, pain management, stress management, goal achievement, other services, and emotional support” (Kealey & McIntyre, 2004, p. 237). The majority score was 4 followed by 3, revealing that the majority of participants and their caretakers were satisfied with the occupational therapy interventions. The occupational therapy interventions have a common goal as well, which is to

improve the life of the individual at the end of life, which is why the results provide further support for this theme.

**Coping with illness at the end of life.** This theme can be found in four of the five articles analyzed in the systematic review. This is likely due to teaching coping techniques and strategies being a common intervention in both occupational therapy and palliative care. In Eriksson et al. (2016), this theme stemmed from two themes developed by the authors of the study, which were “living with disease” and “way to control existence” (p. 544). The theme of living with disease was recurrent in conversations with women who were finding it difficult to maintain their role in their family as the planner, the one who kept everything together, or “the spider in the web” (Eriksson et al., 2016, p. 545). This theme reveals the importance and significance that roles play in occupations. The theme of “way to control existence” was developed through conversations revealing that individuals felt a lack of control, structure, and independence (Eriksson et al., 2016). The use of occupation minimizes these negative feelings, helping individuals cope with their illness at the end of their life.

The theme can also be found in the case report by Kasven-Gonzalez et al. (2009). The theme of having a positive atmosphere was recurrent in this report. A positive atmosphere was achieved by focusing on the wants and needs of the client and the healthcare team maintaining open communication with the family (Kasven-Gonzalez, 2009). The author stated that a positive atmosphere was facilitated at “an otherwise negative time in this patient’s life” (Kasven-Gonzalez, 2009, p. 367). The positive atmosphere was influential in helping the individual to cope with her illness and impending death. A similar theme was drawn from La Cour et al. (2016), and it is called “alternative ways to deal with life” (p. 245). This theme is derived from conversations with participants in the study who engaged in creative activity in occupational

therapy at a palliative care facility. The participants revealed that this was an ongoing process in their life and the creative activity allowed them a safe space to process their illness, cope, and confront their own mortality (La Cour et al., 2016). This relates to an overall theme of coping with illness at the end of life because those are steps in the coping process. Although the data collected in Sakaguchi and Okamura (2015) was quantitative, the results and discussion further support the theme of coping with illness at the end of life as well. In the study, older adults with cancer were prompted to complete a life review and participate in a collage activity. The two interventions together were shown to promote feelings of nostalgia, which brought positive memories at an otherwise negative time of life, helping the individuals to cope with their illness (Sakaguchi & Okamura, 2015).

**Engaging in valued occupations at the end of life.** This theme was seen in three of the articles including Eriksson et al. (2016), Kasven- Gonzalez et al. (2009), and Kealey and McIntyre (2004). The theme of engaging in valued occupations at the end of life was evident in each article. In Eriksson et al. (2016), it appeared when participants discussed feeling a loss of occupations and the negative impact of this loss. In Kasven-Gonzalez et al. (2009), the theme was apparent throughout because the authors reported that the individual receiving occupational therapy was motivated to participate in valued occupations. The author explained that motivation was a key factor for the client, and that the client was more motivated to participate in the occupations that she personally found valuable. In this particular study, the patient developed the occupational and functional goals and was “highly motivated to achieve them” (Kasven-Gonzalez, 2009, p. 367). The occupational therapist and physical therapist modified and adjusted the goals while keeping the focus on the client’s desires, making it clear that engaging in valued occupations at the end of life is a meaningful experience. Kealey and McIntyre (2004) had



similar experiences with the participants in their study. Reoccurring themes from the qualitative research collected were “valued equipment/adaptations” and “access to (occupational therapy) services” (Kealey & McIntyre, 2004). Both of these themes involve methods for participants to engage in valued occupations at the end of their lives.

**Interacting with loved ones and healthcare providers at the end of life.** This theme was evident in four of the five articles chosen for the review, including Eriksson et al. (2007), Kasven-Gonzalez et al. (2009), Kealey and McIntyre (2004), and Sakaguchi and Okamura (2014). In Eriksson et al. (2007), the theme was evident through another theme, “controlling social contacts” (p. 548). This was drawn through participants conveying just how meaningful visits from family and friends were to patients. In Kasven-Gonzalez et al. (2009), the family of the patient was involved with expressing satisfaction with services provided. The author wrote, “patient and her family verbalized appreciation to the therapists for consistently working with her” (Kasven-Gonzalez et al., 2009, p. 367). In this case, interaction between the patient, family, and the healthcare providers was influential. In Kealey and McIntyre (2004), it was evident that participants appreciated and valued the bond they felt with the occupational therapist. This is seen in two themes, which were “quality interaction with the occupational therapist” and “the occupational therapist was understanding” (Kealey & McIntyre, 2004, p. 238). These themes reveal that interactions with healthcare providers, whether they are occupational therapists or not, has an impact on the lives of patients receiving palliative care. Results and discussion points from Sakaguchi and Okamura (2014) further support this theme. The families of the individuals participating in the life review and collage activity were involved as well. It was shown that this was a positive experience for all those involved, providing support for the claim that interactions with loved ones and healthcare providers at the end of life is impactful.

Table 3. Synthesis and Analysis of Qualitative Themes

| <b>Theme</b>  | <b>Eriksson et al. (2016)</b>                       | <b>Kasven-Gonzalez et al. (2009)</b>                    | <b>Kealey &amp; McIntyre (2004)</b>                            | <b>La Cour et al. (2007)</b>                  | <b>Sakaguchi &amp; Okamura (2014)</b>           |
|---|---|---|--|---|---|
| <b>1</b><br>Improving life at the end of life                                       |   | - Relief from distressing symptoms                      | - Satisfaction with OT services                                | - Easing life before death                    |   |
| <b>2</b><br>Coping with illness at the end of life                                  | - Living with disease<br>- way to control existence | - Positive atmosphere promotes improved quality of life |  | - Alternative ways to deal with life (coping) | - Promoting feelings of nostalgia               |
| <b>3</b><br>Engaging in valued occupations at the end of life                       | - Loss of occupations                               | - Motivation for valued occupations                     | - Value equipment/adaptations<br>- Access to service           |   |   |
| <b>4</b><br>Interacting with loved ones and healthcare providers at the end of life | - Controlling social contacts                       | - Verbal appreciation for OT/PT services                | - Quality interaction with therapist<br>- OT was understanding |   | - Involving family members in creative activity |

## Discussion

The results of the systematic review reveal that occupational therapy is an effective method of care within palliative care for patients with cancer. Based on the identified articles, occupational therapy had a positive impact on the lives of the individual. Since a majority of the studies collected qualitative data, new themes were developed by the author in an effort to connect all of the studies. There were four themes developed: 1) improving life at the end of life; 2) coping with illness at the end of life; 3) engaging in valued occupations at the end of life; 4) interacting with loved ones and healthcare providers at the end of life. These themes were evident across each of the five articles utilized in the systematic review. Although the methods and goals of each study were vastly different, the results of each supported one or more of these themes, revealing that the articles were more alike than different.

The common thread among the themes is overall improvement of quality of life. This can be seen in other articles and studies pertaining to occupational therapy and palliative care that did not meet the inclusion criteria for this review. For example, in 2014, a systematic review was conducted on the effectiveness of occupational therapy interventions for patients with Amyotrophic Lateral Sclerosis (ALS), which is a terminal illness (Arbesman & Sheard, 2014). This systematic review analyzed studies focused on individuals with ALS receiving occupational therapy services at any point in their illness. The results indicated that occupational therapy was a beneficial service for those individuals in the terminal stage of ALS who were also receiving palliative care with positive outcomes such as overall improved quality of life, independence with assistive devices, positioning for comfort, and addressing physical and emotional distress (Arbesman & Sheard, 2014).

Palliative care has been proven to be beneficial for individuals with cancer because it

reduces distressing physical and psychological symptoms (Howie & Peppercorn, 2013). Early intervention with palliative care for individuals with cancer has also been shown to be effective in improving outcomes, quality of life, and potentially survival (Howie & Peppercorn, 2013). Overall, it is clear that palliative care has a vast, positive impact on the individual receiving care and their family. The ultimate goal of occupational therapy is to increase an individual's participation in the activities or occupations that they find valuable with adaptations if necessary (AOTA, 2014). In the context of oncology, occupational therapy is a valuable method of care for individuals with cancer. The purpose of occupational therapy in oncology is to improve function, maintain independence, promote wellness, reduce cognitive deficits due to chemotherapy, and improve overall quality of life (Longpre & Newman, 2011). Cancer is an epidemic in the United States and results in significant declines in function and quality of life. Both occupational therapy and palliative care have been proven to improve function and life quality for patients with a variety of conditions. However, prior to this systematic review, there was not a compilation of literature that revealed the effectiveness of incorporating occupational therapy in palliative care.

As previously stated, occupational therapy within palliative care is also an area for further research, especially within the United States. Both palliative care and occupational therapy are growing professions in the nation. Both professions are also looking to expand the field, and collaboration between these professions may be an appropriate way to do so. This would result in improved quality of life for those receiving services, as indicated by the results of this systematic review. As shown in the study by Aberbesman and Sheard (2014), the combination of occupational therapy and palliative care would not only be beneficial for individuals with cancer,

but also for individuals with ALS and other terminal or serious illnesses. Further research is necessary in this area as well.

### **Limitations**

A limitation to this systematic review is that the author could only choose articles and studies written in or translated to the English language. Articles written in different languages were disregarded in the search and selection process. Another major limitation in this systematic review is that many of the articles and studies, 4 out of 5, were not based in the United States; 2 studies were conducted in Sweden, 1 study was completed in the United Kingdom, and the final study was completed in Japan. This is an area for future research within the United States. Next, a possible limitation is that each of the articles identified revealed positive results, meaning there could be a publication bias. Journals are less likely to publish studies that have negative results, and these studies would not be available for inclusion in the review. Finally, due to the diversity of studies identified and analyzed, it was impossible for the author to assess and compare the quality across studies. Although there are assessments, such as the PEDro assessment for randomized control trials and other assessments for qualitative data, there was not uniformity in the articles selected for the review, so these tools could not be utilized across articles (Maher et al., 2003). Similarly, meta-analysis was also not possible due to a limited number of studies on the subject and diversity of research methods across the studies selected.

### **Implications and Conclusion**

The results of this systematic review reveal that occupational therapy would be a beneficial service for individuals with cancer who are also receiving palliative care. The occupation-based service is not only helpful in maintaining the roles of the individual, but it is also effective in giving purpose and meaning to terminally ill individuals. Palliative care is

currently delivered by a multi-disciplinary team, but occupational therapists are not typically a part of this approach. Based on the results drawn from this review, occupational therapists would be an effective member to add because the services provided increased the quality of life for individuals with cancer. With the growth of palliative care programs in the United States, occupational therapists could potentially impact the lives of many. Palliative care already has a vast influence on not only the individual receiving care but also the family of the individual. This is an area for further research in the United States.

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