

2016

# Characteristics of the Informal Caregiver: An Integrative Literature Review

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# Walden University

College of Health Sciences

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Jonanna Bryant

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Walden University  
2016

Abstract

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by

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MSN, Walden University, 2011

MS, Cairn University, 2005

BSN, College of New Rochelle, 1991

Project Submitted in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Nursing Practice

Walden University

May 2016

## Abstract

The needs of the informal caregiver can be difficult to determine apart from those related to caring for the terminally ill loved one. Often, informal caregivers' individual needs are lost because of their day-to-day responsibility and care of their terminally ill loved one. The purpose of this project was to discover the characteristics of informal caregivers of the terminally ill. An integrated literature review was conducted using the Fineout-Overhalt, Melnyk, Stillwell, and Williamson's (2010) analytical approach to reviewing the evidence. The approach consisted of 7 levels for evaluating the hierarchy of evidence. Inclusion criteria were studies limited from January 2004 to October 2015, English language, and full text. A total of 22 studies were reviewed and categorized according to 1 of the 7 hierarchical levels, and findings related to the characteristics of informal caregivers were summarized at each appropriate level. Characteristics of informal caregivers were described regarding sociodemographics, such as age, gender, relationship with family members, financial status, and educational level. Characteristics of informal caregivers were discussed in relationship to the terminally ill loved one. The evidence did not concentrate on who the informal caregiver was without assessing their relationship to the terminally ill patient. It is recommended that a mixed-method approach be conducted to identify characteristics of informal caregivers outside of their relationship with the terminally ill. Gaining a new perspective about the characteristics of informal caregivers for the terminally ill patient would help health care providers to more effectively meet their needs independent of the needs of the terminally ill loved one.

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In Memory Of

William M. Anderson

1947-2013

You will always be in my heart.

Dedication

I dedicate this project to all of those who have taken care of their terminally ill loved ones, neglecting your own life, wealth, health and well-being. Your willingness to sacrifice all to care for your loved one is unmatched and will always resonate in the hearts of your family.

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## Section 1: Nature of the Project

### **Introduction**

The National Alliance for Caregiving (2009) estimated that there were approximately 36 million adults providing care to someone over 65 years of age. The demand for informal caregivers was directly linked to a steady increase in persons over 65 years of age (CDC Prevention and the Kimberly-Clark Corporation, 2008). Between 2000 and 2030, the estimated number of persons over the age of 65 will rise at the rate of 2.3% each year (CDC and the Kimberly-Clark Corporation, 2008). Unfortunately, the number of informal caregivers would only increase at 0.8% per year over the same timeframe (CDC and the Kimberly-Clark Corporation, 2008). Many caregivers are not able to care for their loved ones at home. Therefore, placing them into a nursing facility may be their only option.

Pennsylvania was ranked fourth in the country with the percentage of its population over the age of 65 (Choosing a nursing home, n.d.). Because of its large aging population, Pennsylvania has over 700 nursing homes for caregivers to choose from for their loved ones. As of March 2009, more than 81,000 Pennsylvanians were placed in nursing homes for various reasons (Choosing a nursing home, n.d.). Not all residents of nursing homes had loved ones to check on their well-being or to see about their financial affairs. However, many residents had family that visited, cared, and were considered their responsible party/person for contact.

According to Code of Federal Regulations §483.30(b), also known as F-tag F354, each nursing home must have a director of nursing (DON) to oversee the nursing

department and the care and services that they render which includes resident care. In reference to the residents, the DON is responsible to ensure that all residents receive the care and services they need and deserve. In assisting residents to attain or maintain their “highest practicable physical, mental and psychosocial well-being” (Electronic Code of Federal Regulations, 2015), the DON along with other staff members interact with the responsible party/person also known as the informal caregiver. Regardless of where the resident lives, the life of a caregiver is understandably stressful. The informal caregiver’s feelings of being stressed and overwhelmed are common with loved ones who are terminally ill. Costa and Othero (2012) defined terminal illness as having an illness or disease that is not curable and will lead to death in 3 to 6 months.

The effects of being an informal caregiver manifested in many forms. When the informal caregiver cared for others who were terminally ill it produced stress, anxiety, exhaustion, and depression (Candy, Jones, Drake, Leurent, & King, 2011). Caregiver burden was another feeling that informal caregivers experienced. Informal caregivers experience caregiver burden differently from everyday stressors (Collins & Swartz, 2011). Grant et al. (2013) described caregiver burnout as distress that arose because of providing care for chronically or terminally ill loved ones with seemingly little relief. The distress experienced by the informal caregiver was different from the feelings of depression, anxiety and other emotional responses (Grant et al., 2013). Individual caregiver’ feelings toward their terminally ill loved one vary. However, the experiences of the informal caregiver’s stress are vastly different from every day stress and stressors that are unrelated to caregiving responsibilities.

Girgis, Lambert, Johnson, Waller, and Currow (2013) completed a review of informal caregivers for people with cancer. Their focus regarding the informal caregiver was to provide an overview concerning the issues informal caregivers faced while providing care to persons with cancer. Grant et al. (2013) discussed informal caregiver burden for patients with nonsmall-cell lung cancer. They determined that because of the high level of burdens that was experienced by the informal caregiver, it was imperative that interventions for support for the caregiver be developed and implemented.

There was a large body of literature that addressed aspects of caregiving. Caregiver burnout was discussed by Proot et al., (2003), Chesney, Neilands, Chambers, Taylor and Folkman, (2006), McDaniel and Allen, (2012), Emanuel et al., (2008), and van Ryn et al., (2010). Cancer was discussed in relationship to caregivers (Flaskerud, Carter, & Lee, 2000; Girgis et al., 2013; Grant et al., 2013; Lee et al., 2013; Mon et al., 2012; Northfield & Nebauer, 2010). Stress and the caregiver was discussed by Empeno, Raming, Irwin, Nelesen, and Lloyd (2011), Kutner et al. (2009), Gallagher-Thompson and Powers (1997), Townsend, Ishler, Shapiro, Pitorak, and Matthews (2010), Kulkarni et al. (2014), Smith, Williamson, Miller, and Schulz (2011), Mackenzie, Smith, Hasher, Leach, and Behl (2007), Bainbridge, Krueger, Lohfeld, & Brazil (2009) and Washington, Demiris, Oliver, Wittenberg-Lyles, & Crumb (2012). Finally, Mystakidou et al. (2013) described the feelings of the primary caregiver for patients with dementia and Alzheimer's disease to include anxiety, depression, emotional stress, isolation, hopelessness, and helplessness.

Several authors addressed caregiver burdens (Brink, Stones, & Smith, 2012), stress (Bainbridge et al., 2009), and characteristics of being an informal caregiver (Waldrop, Kramer, Skretny, Milch, & Finn, 2005; Burns C. M., LeBlanc, Abernethy, & Currow, 2010). Little information existed that discussed characteristics regarding the informal caregiver. Furthermore, none of these authors discussed informal caregivers, independent of the terminally ill loved ones that they care for. At the time of this study, there was little information discovered regarding the characteristics of the informal caregiver independent of the terminally ill patient.

### **Problem Statement**

There was little evidence regarding the characteristics of the informal caregiver apart from the terminally ill patient. The informal caregiver of the terminally ill faced a myriad of feelings and responsibilities. The informal caregiver must take care of his or her personal life, which may have included attending to children and spouse, meeting employment responsibilities as well as care for their terminally ill loved one. However, understanding the informal caregiver's characteristics was difficult because it intertwined with the care and responsibilities of caring for their loved one. As a result, it was difficult to distinguish the characteristics of the caregiver.

The DON interacts nearly daily with an informal caregiver regarding the care and services provided to their loved one (V. Lyons, personal communication, January 16, 2016). As the DON, he or she was often unaware of the family dynamics, which may affect informal caregivers. Upon expressing their concerns to the DON, informal caregivers were angry, frustrated, and dissatisfied about the care and services their loved

one is receiving (V. Lyons, personal communication, January 16, 2016). The feelings of an informal caregiver heightened when their loved one was terminally ill. The DON must be able to recognize the stages of grief the informal caregiver maybe exhibiting at the time of their interaction.

Kübler-Ross (EKR Foundation, n.d.) determined that there were five stages of grief, (a) denial, (b) anger, (c) bargaining, (d) depression, and (e) acceptance. There are some instances where the informal caregiver never reaches acceptance in relationship to the terminally ill loved one (EKR Foundation, n.d.). This failure to move through the grieving process is often times deflected on the nursing staff and at the DON (V. Lyons, personal communication, January 16, 2016).

### **Purpose**

The purpose of this DNP project was to conduct an integrative review of literature to identify characteristics of informal caregivers of the terminally ill. The needs and characteristics of the informal caregiver and the terminally ill patient were not discussed independently of each other. The characteristics of the informal caregiver were difficult to determine apart from those whom they care for on a regular basis. The number of informal caregivers will increase greatly as the baby-boomer generation ages (CDC and the Kimberly-Clark Corporation, 2008). It was estimated that between 2000 and 2030 there would be a 2.3% increase of those over the age of 65 (CDC and the Kimberly-Clark Corporation, 2008). Although the number of persons turning 65 will increase, the number of informal caregivers would only increase by 0.8% during the same timeframe (CDC and the Kimberly-Clark Corporation, 2008).



This DNP project has the potential to assess the gap in literature related to the characteristics of the informal caregiver independent of the terminally ill loved one, for the nursing community. Use of the information gained would assist the nursing community in taking a holistic approach to care, which includes both the patient and their loved one. A holistic approach would take into consideration the needs of the informal caregiver as well as the needs of the terminally patient.

### **Nature of the Doctoral Project**

In this DNP project, I conducted an integrative review of literature. Oermann and Hays (2011) described systematic reviews as the author's attempt to answer specific questions regarding clinical or research problem. A systematic and rigorous analysis of the current literature regarding the characteristics of the informal caregiver apart from the terminally ill patient was conducted.

The framework for this project followed Fineout-Overhalt et al. (2010) approach to conducting a critical appraisal of the literature. Fineout-Overhalt et al. suggested that there were seven levels of evidence in which to categorize articles. These were (a) systematic review or meta-analysis, (b) randomized controlled trial, (c) controlled trial without randomization, (d) case-control or cohort study, (e) systematic review of qualitative or descriptive study, (f) qualitative or descriptive study, and (g) expert opinion or consensus (Fineout-Overhalt et al, 2010). I utilized a grid-layout method to distinguish the appropriate category for each article. Findings from the articles were summarized within each category.

Caring for the terminally ill patient generated a wide variety of emotions and had an adverse effect on the informed caregiver's health (Abernethy, Burns, Wheeler, & Currow, 2009). The informal caregiver experienced emotions such as anger, anxiety, fear, disbelief, guilt, resentment, hopelessness, and helplessness (Mystakidou et al., 2013). The needs of the informal caregiver were vast. Careful depiction of the characteristics of the informal caregiver will assist the advanced nurse practitioner to identifying resources to be of assistance to them (Girgis et al., 2013).

Nurses have an opportunity to meet the need of the informal caregiver by offering them a variety of services through referral as they care for their terminally ill loved ones. However, in order to meet that need, one must understand the caregiver's needs apart from the terminally ill loved one. Helping the informal caregiver to manage their feelings of anxiety, exhaustion, depression, and caregiver burnout during this difficult time will help them be better caretakers for themselves and for their loved ones.

### **Significance**

Informal caregiver's emotions varied and had significant effects on their personal health (Abernethy et al., 2009). Anger, fear, guilt, disbelief, resentment, hopelessness, and helplessness were feelings informal caregivers experienced (Mystakidou et al., 2013). In order for the nursing community to identify the appropriate resources for informal caregivers, a careful depiction of the characteristics of the informal caregiver must be assessed (Girgis et al., 2013). Based on the status of the terminally ill loved one, informal caregivers' needs vary and change (Proot et al., 2003). Ensuring that the caregiver's needs were met was essential to the care they provided to their loved ones.

There are several organizations that are available for informal caregivers to access that may serve as a resource. American Association of Retired Persons (AARP, n.d.) and Family Caregiver Alliance are just two of them. AARP (n.d.) was the most familiar to a large amount people. AARP's website (n.d.) offered a list of agencies for persons to contact that could render assistance. However, this site may be considered as a site designed for retired persons and not as a site that could assist in caring for chronic or terminal patients. The site also may not be visited by those who are not of retirement age. The Family Caregiver Alliance (Family Caregiver Alliance, n.d.) may not be well known among the general population. This site strived to educate the informal (family) caregiver through information, servicers (locally, regionally, and nationally) and advocacy (Family Caregiver Alliance, n.d.). Each organization offered information regarding the care and services for the chronically ill patient, but a review of their website did not render information regarding the characteristics of informal caregivers independent of their terminally or chronically ill loved ones.

In this DNP project, I examined characteristics of the caregiver of the terminally ill patient through the literature. This DNP project could provide crucial information to assist caregivers, nurses, patient care facilities, and various stakeholders to meet the needs of infomal caregivers. A fresh perspective regarding the characteristics of informal caregivers would help to meet the needs of the caregiver independent of the terminally ill patient.

Informal caregivers have feelings of inadequacies and stress as well as suffering from poor health while caring for their loved ones (Candy et al., 2011; Janze &

Henriksson, 2014). Improving the health and well-being of the informal caregiver could imply that their overall outlook on life and the care provided would be positive. The caregiver's outlook on life and the care provided for their terminally ill loved ones could potentially improve.

### **Definitions of Terms**

*Caregivers:* Caregivers are described as a person who provided care and services to persons who are chronically or terminally ill who were in need (Collins & Swartz, 2011) of assistance with their activities of daily living. Caregivers are typically female who are over the age of 69 (Collins & Swartz, 2011). Caregivers are often related to the ill person, but could also be a family friend or neighbor who agree to take on that role and responsibility.

*Director of Nursing (DON):* The DON is the person who is responsible for the overall care and services rendered to residents in a nursing facility (Electronic Code of Federal Regulations, 2015). He or she is a registered nurse and has several assistants who act as a proxy in his/her absence.

*Formal Caregiver:* The formal caregiver is a person who receives some type of payment for rendered care to the terminally ill person (Joyce, Berman, & Lau, 2014). This person can be a home health aide, certified nursing assistant or a registered nursing assistant (Joyce et al., 2014). The formal caregiver renders care in homes, hospitals, nursing homes and other types of care facilities (Joyce et al., 2014). Unlike the informal caregiver, the formal caregiver has routine days off and vacations (Joyce et al., 2014).

*Informal Caregiver:* An informal caregiver is a person who rendered care and

services to a person without payment (Collins & Swartz, 2011; Family caregiver alliance, 2004). He or she could be related to the terminally ill person, such as a spouse, child, sibling, or another relative. On the other hand, the informal caregiver could be a family friend or neighbor. Generally, the informal caregiver provided care and services to the patient in their homes.

*Responsible Party/Person:* A responsible party/person is considered to be an individual who is deemed responsible for his or her loved ones medical and/or financial well-being (Electronic Code of Federal Regulations, 2015). This person may or may not have medical or dual power of attorney for the ill patient (Electronic Code of Federal Regulations, 2015). He or she accepts the responsibility to be the point of contact for his or her loved one (Electronic Code of Federal Regulations, 2015).

*Terminally Ill:* Terminally ill is not limited to any one particular diagnosis. A terminally ill person is identified as a person deemed by a physician to have reached the terminal stage of an illness or disease (Caregiver burden of terminally-ill adults in the home setting, 2012). A terminal illness is not relegated to cancer or AIDS (Acquired Immune Deficiency Syndrome) (Caregiver burden of terminally-ill adults in the home setting, 2012). A terminal illnesses include but are not limited to, heart disease, dementia, diabetes, and so forth (Caregiver burden of terminally-ill adults in the home setting, 2012). Regardless of the diagnosis, it is the physician's determination that the patient was terminally ill. For this project, terminal illness is defined as having an illness or disease that was not curable and would lead to death in 3 to 6 months (Costa & Othero, 2012).

**Summary**

The life of an informal caregiver is stressful and caused increased in symptoms related to physical, mental, and financial strain (Grant et al., 2013). However, characteristics of the informal caregiver apart from the terminally ill loved are difficult to articulate based on the current literature. A systematic literature review of the characteristics of the informal caregiver would assist in identifying the appropriate support needed for them during their time of caring for others and neglecting self. There was an abundance of literature addressing, caregiver burnout and stress in relationship to the terminally ill patient. However, there was a paucity of literature examining characteristics of the informal caregiver exclusive of their relationship to the terminally ill patient. A systematic review of the literature was conducted to identify what was known about characteristics of informal caregivers in order to provide recommendations for practice, policy, and additional research.

## Section 2: Background and Context

### **Introduction**

During the final months and days of a terminal ill patient, informal caregivers face an array of feelings and responsibilities. They are responsible for their personal life as well as the life of the terminally ill patient. However, little is known about the characteristics of the informal caregiver apart from the terminally ill loved one. The benefits to the nursing community to further investigate the characteristics of the informal caregiver in order to provide them with access to care and services that would benefit them. Providing the informal caregiver with the means to help themselves, would have a positive impact on the person they were responsible for ensuring that they received the care and services that was needed.

This DNP project would assist the nursing community, in particular the DON, to understand the characteristics of informal caregivers apart from terminally ill patients. Addressing the whole person, which included informal caregivers, was important for both the patient and the informal caregiver (Collins & Swartz, 2011). Section 2 reviewed review the following segments: (a) literature search strategy used within Walden University's library, (b) framework, utilizing Fineout-Overhalt, Melnyk, Stillwell, and Williamson's (2010) system (c) how the characteristics of the informal caregiver was relevant to the nursing community, and (d) my role with the DNP project regarding the characteristics of the informal caregiver.

## **Literature Search Strategy**

A literature search was conducted through Walden University's library. The database searched included, CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE (Medical literature), MEDLINE with full text, Academic Search Complete, PsychArticles (American Psychological Association Articles), ERIC (Education Resources Information Center), SocIndex (Sociology Index) with full text and PsycINFO (Psychological Information).

The search words utilized were *informal caregivers*, *formal caregivers*, *terminally ill*, and *characteristics*. Excluded words were *children*, *child*, and *youth*. Search terms consisted of *informal caregivers + terminally ill*, *formal caregivers + terminally ill*, *informal caregiver + stressors*, *informal caregiver + hospice and stress process model + caring*. Articles were excluded from this review if they were not published in English between January 2004 and October 2015.

## **Framework for DNP Project**

The framework that was used to analyze the hierarchy of evidence was described by Fineout-Overhalt et al. (2010). Listed below is Fineout-Overhalt et al.'s defined framework for the evaluating the hierarchy of evidence:

- Level I: Evidence found through a systematic reivew or meta-analysis of all relevant randomized controlled trials;
- Level II: Evidence found through subjects that are randomized to a treatment group or a control group;



- Level III: Evidence found through subjects that are not randomly assigned to a treatment group or control group;
- Level IV: Evidence found through a case-control study or cohort study;
- Level V: Evidence found through qualitative or descriptive studies which answer a clinical question;
- Level VI: Evidence found through qualitative studies or descriptive studies;
- Level VII: Evidence found through the opinions of expert committees.

For this project, I was responsible for conducting the integrative review by following all the steps outlined in Section 3.

### **Relevance to Nursing Practice**

Care for the terminally ill patient generated a wide variety of emotions and had an adverse effect on the informal caregiver's health (Abernethy et al., 2009). Informal caregivers experienced emotions such as anger, anxiety, fear, disbelief, guilt, resentment, hopelessness, and helplessness (Mystakidou et al., 2013). The needs of the informal caregiver are vast. Careful depiction of the characteristics of the informal caregiver would assist the nursing community in identifying resources to be of assistance to them (Girgis et al., 2013). Informal caregivers of the terminally ill faced a myriad of feelings and responsibilities. He or she must take care of their personal life, which included attending to children and spouse, meeting employment responsibilities, as well as ensuring that their loved ones are cared for adequately.

The informal caregiver could be a spouse, child, sibling, family member, or family friend. A caregiver was one who tended to the needs of the person who was dependent upon someone else for care. The needs of the patient consisted of assisting with activities of daily living, financial management, or activities designed to foster the social, spiritual, and emotional well-being of the terminally ill person. Informal caregivers were more than caretakers of the patient who was terminally ill and actively dying, they were individuals with feelings and concerns (Abernethy et al., 2009). They had a close and personal relationship with patient which increased the amount of burden that felt by the informal caregiver. In contrast, the formal caregiver was a skilled laborer who was trained to care for the sick, infirmed, and terminally ill patients.

There were approximately 42.1 million adults considered caregivers in the United States (Margesson, 2013). Caregivers, for the most part, were in good health (Empeno et al., 2011). According to Beland (2013), many patients diagnosed with a terminal illness would like to die at home. However, they required a family member, friend, or neighbor who would be willing to assist in that process. The caregiver's willingness to care for the terminally ill patient at home hampered his or her own illnesses, financial instability, and family dynamics (Beland, 2013). Although the desire for the informal caregiver to fulfill the wishes of the terminally ill loved one may be great, emotionally they may not be able to continue caregiving for them when death was near (Beland, 2013). However, informal caregivers were more likely to exhibit signs and symptoms of depression and/or anxiety and incurred long-term health issues such as heart disease, cancer, arthritis, or diabetes (Empeno et al., 2011) as time progressed with their loved ones. Support for the caregiver

was essential for their wellbeing while attending to the care of the terminally ill patient. Support could be in the form of support group, one-on-one or family counseling, respite care, as well as direct services, such as food or meal preparation and housekeeping.

### **Role of the DNP Student**

My motivation in relationship to this DNP project was very personal. In 2013, my uncle was given less than 6 months to live. He had end-stage liver failure and heart failure from years of substance abuse. Although my uncle was legally married and had a son, his sister and I were deemed the responsible party and informal caregivers. When my uncle was hospitalized and subsequently placed in an in-house hospice facility, my mother was out of the country, I had recently started a new job and had just begun my doctoral studies at Walden University. I was extremely stressed and frustrated and felt that no one was concerned about the family as a whole independent of my uncle who was actively dying. My interest in this project was to determine what evidence was currently available to the nursing community that would embrace the whole patient, including the family, during one of the most difficult times of their lives.

### **Summary**

Caregiving, whether formal or informal, was taxing to the mind, body, and soul (Bee, Barnes, & Luker, 2008). The stress from caregiving heightened when caring for a person who was terminally ill. Exacerbation of stress and feelings of inadequacies were also associated with informal caregiving (Abernethy et al., 2009). Caregivers who constantly gave of their time, finances, and energy negate themselves and their needs along with their family needs. Not addressing the needs of the caregiver caused mental

and physical distress, which inadvertently could be projected onto the terminally ill patient. It was important that not only did the patient receive the care and services that they need, but the caregiver must also take the time to get the services, care, and attention that they need and deserve. There was a gap with what was known about the characteristics of the informal caregiver separate from the terminally ill patient. Discovering the characteristics as identified by the integrative literature review would assist the nursing community in providing information that would best fit the life of the informal caregiver.

## Section 3: Collection and Analysis of Evidence

### **Introduction**

The purpose of this project was to conduct an integrative review of literature to identify characteristics of informal caregivers of the terminally ill. Caring for the terminally ill patient generates a wide variety of emotions and can have an adverse effect on the informal caregiver's health (Abernethy et al., 2009). The informal caregiver can experience emotions such as anger, anxiety, fear, disbelief, guilt, resentment, hopelessness, and helplessness (Mystakidou et al., 2013). The needs of the informal caregiver can be vast and complex. Careful depiction of the characteristics of the informal caregiver will assist the nursing community in identifying resources to be of assistance to them during a difficult moment in their life (Girgis et al., 2013). Section 3 will review the following (a) practice-focused problem inquiry, (b) project approach, (c) institutional review board, (d) method used, and (e) a rationale as to why an article were excluded.

### **Practice-Focused Problem Inquiry**

Caregivers were described in many ways in that identifying their characteristics apart from their terminally ill loved one was complicated. Caregivers were under a great deal of stress and feelings of inadequacies (Abernethy et al., 2009). Nevertheless, there was little information available regarding their characteristics. Identifying their characteristics would help the nursing community to better assist the caregiver with care and services. Improving their overall well-being would assist in ensuring that the terminally ill patient was well cared for, whether in the home or in a nursing facility.

## **Project Approach**

An integrative literature review was used for this DNP project. Bettany-Satltikov (2012) indicated that in order to utilize the integrative literature review approach, the reviewer must identify, select, appraise, and synthesize literature regarding a particular subject matter. Utilizing this approach, one must acknowledge the method by which evidence must be appraised. Fineout-Overhalt et al., (2010) ascertained that there were seven levels for evaluating the hierarchy of evidence for articles:

- Level 1 evidence was: a systematic review or a meta-analysis review.
- Level 2 evidence was randomized controlled trial.
- Level 3 evidence was controlled trial without randomization.
- Level 4 evidence was case-control or cohort study.
- Level 5 evidence was systematic review of qualitative or descriptive studies.
- Level 6 evidence was qualitative or descriptive study
- Level 7 evidence was expert opinion or consensus.

Each article to weighed against each of these levels and categorized accordingly. The findings were summarized within each level. Recommendations for nursing practice, policy and futher reasearch were developed.

## **Institutional Review Board**

An Institutional Review Board (IRB) was not required for this DNP project because it did not incorporate human subjects nor used potentially identifying information. This DNP project consisted of an integrative review of the published

literature; therefore it was exempt from Walden University's IRB review. However, Walden University's IRB Form A (preliminary review form) was completed and submitted for review and was accepted. The IRB approval number is 04-06-16-0179569.

## Method

A literature search was conducted through Walden University's library. The database searches included CINAHL, MEDLINE, MEDLINE with full text, Academic Search Complete, PsychArticles, ERIC, SocIndex with full text, and PsychINFO. The search strings utilized were as follows: *informal caregiver + terminally ill, formal caregivers + terminally ill, informal caregiver + stressors, informal caregiver + hospice, and characteristics + caregiver + informal + terminally ill.*

The literature search yielded 77 articles. The searches were limited to January 2004 through October 2015, written in the English language, full text articles and excluded reference to children under the age of 18. Forty-four out of 77 articles were excluded based on the exclusion criteria (Table 1). There were 33 articles were analyzed.

**Table 1**

*Table of Article Exclusion*

Study, year (Reference)	Article	Rationale for Exclusion
Agar et al. (2008)	Preference for place of care and place of death in palliative care: are these differnt questions?	Discussed choice of where to die for terminally ill patient
Albers, de Vet, Pasman, Deliens, & Onwuteaka-Philipsen (2013)	Personal dignity in the terminally ill from the perspective of caregivers: A survey among trained volunteers and physicians	Discussed dignity related to patient

(table continues)

<b>Study, year (Reference)</b>	<b>Article</b>	<b>Rationale for Exclusion</b>
(Angelo, Egan, & Reid (2013)	Essential knowledge for family caregivers: a qualitative study	Discussed formal caregivers
Beccaro, Monica; Costantini, Massimo; Merlo, Domenico; ISDOC STUDY GROUP (2007)	Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC)	Discusses terminally ill patient not informal caregiver
Burns M. , LeBlanc, Abernethy, & Currow (2010)	Young caregivers in the end-of-life setting: A population-based profile of an emerging group	Some study participants were under 18 years of age
Cartwright et al. (2007)	Physician discussions with terminally ill patients: a cross-national comparison	Discusses terminally ill patient not informal caregiver
Chesney et al., (2006)	A validity and reliability study of the coping self-efficacy scale	Discussed patient's coping
Chochinov, H., & Cann, B. (2005).	Interventions to enhance the spiritual aspects of dying	Discusses terminally ill patient not informal caregiver
Choi, Donahoe, Zullo, & Hoffman (2011)	Caregivers of the chronically critically ill after discharge from the intensive care unit: Six months' experience.	Discusses chronically ill patient and not terminally ill
Chronister & Chan (2006)	A stress process model of caregiving for individuals with traumatic brain injury	Does not refer to terminally ill patients
Costantini, Di Leo, & Beccaro (2011)	Methodological issues in a before-after study design to evaluate the Liverpool care pathway for the dying patient in hospital	Discusses the terminally ill patient
Currow et al. (2008)	Do terminally ill people who live alone miss out on home oxygen treatment? A hypothesis generating study	Discusses the terminally ill patient

(table continues)



<b>Study, year (Reference)</b>	<b>Article</b>	<b>Rationale for Exclusion</b>
Dosser & Kennedy (2012)	Family carers' experiences of support at the end of life: carers' and health professionals' views	Discussed bereaved informal caregiver
Galfin, Watkins, & Harlow (2010)	Psychological distress and rumination in palliative care patients and their caregivers	Discussed psychological distress related to patient
Giesbrecht, Crooks, & Williams (2010)	Scale as an explanatory concept: Evaluating Canada's compassionate care benefit	Evaluation of Canada's palliative care
Gu, Cheng, Chen, Liu, & Zhang (2015)	Palliative sedation for terminally ill cancer patients in a tertiary cancer center in Shanghai, China.	Refers to the terminally ill patient
Hackett & Palmer (2010)	An investigation into the perceived stressors for staff working in the hospice service	Stress related to hospice nurses
Hawkins, Howard, & Oyeboode (2007)	Stress and coping in hospice nursing staff. The impact of attachment styles	Stress and coping experiences with hospice nurses
Heyland et al. (2010)	The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: the Canadian Health Care Evaluation Project (CANHELP) Questionnaire	Discusses patient and family satisfaction with care
Joad, Mayamol, & Chaturvedi (2011)	What does the informal caregiver of a terminally ill cancer patient need? A study from a cancer centre	Discusses the informal caregiver during bereavement
Joyce, Berman, & Lau (2014)	Formal and informal support of family caregivers managing medications for patients who receive end-of-life care at home: A cross-sectional survey of caregivers.	Discusses medication management with informal caregiver
Klinger, Howell, Zakus, & Deber (2014)	Barriers and facilitators to care for the terminally ill: A cross-country case comparison study of Canada, England, Germany and the United States.	Refers to the terminally ill patient

(table continues)

<b>Study, year (Reference)</b>	<b>Article</b>	<b>Rationale for Exclusion</b>
Knight & Emanuel (2007)	Processes of Adjustment to End-of-Life Losses: A reintegration model	Refers to the terminally ill patient
Kutner et al., (2009)	Support needs of informal hospice caregivers: A qualitative study	Discusses the informal caregiver during bereavement
Lee et al. (2013)	Longitudinal changes and predictors of caregiving burden while providing end-of-life care for terminally ill cancer patients	Discusses the informal caregiver during bereavement
Mahtani-Chugani, Gonzalez-Castro, Saenz de Ormijana-Hernandez, Martin-Fernandez, & Fernandez de la Vega (2010)	How to provide care for patients suffering from terminal non-oncological diseases: Barriers to palliative care approach	Discusses the terminally ill patient not caregiver
McDaniel & Allen (2012)	Working and care-giving: The impact on caregiver stress, family-work conflict, and burnout	Discusses caregiver in relationship to chronic illness
Mon et al. (2012)	Characteristics of caregiver perception of end-of-life caregiving experiences in cancer survivorship: in-depth interview study	Discusses the informal caregiver during bereavement
Morin, Saint-Laurent, Bresse, Dallaire, & Fillion (2007)	The benefits of a palliative care network: A case study in Quebec, Canada	Discusses benefits of palliative care
Muller-Mundt et al. (2013)	End of life care for frail older patients in family practice (ELFOP)-protocol of a longitudinal qualitative study on needs, appropriateness and utilisation of services.	Discusses the terminally ill patient

(table continues)

Study, year (Reference)	Article	Rationale for Exclusion
Nakamura, Kuzuya, Funaki, Matsui, & Ishiguro (2010)	Factors influencing death at home in terminally ill cancer patients.	Discusses the terminally ill patient
Pinquart & Duberstein (2005)	Optimism, pessimism, and depressive symptoms in spouses of lung cancer patients	Discussed chronically ill patient not terminally ill patient
Rodriguez & King (2014)	Sharing the care: the key-working experiences of professionals and the parents of life-limited children	Discussed pediatric end of life
Russell, Rowett, & Currow (2014)	Pro re nata prescribing in a population receiving palliative care: A prospective consecutive case note review	Discussed pain management
Stiel, Heckel, Bussman, Weber, & Ostgathe (2015)	End-of-life care research with bereaved informal caregivers- analysis of recruitment strategy and participation rate from a multi-centre validation study.	Discusses the informal caregiver during bereavement
Thooneses et al. (2011)	Early identification of and proactive palliative care for patients in general practice, incentive and methods of randomized controlled trial	Discuss palliative care for patients
Tran, Johnson, Fernandez, & Jones (2010)	A shared care model vs. a patient allocation model of nursing care delivery: Comparing nursing staff satisfaction and stress outcomes.	Discusses nursing staff satisfaction
Tse, Wu, Suen, Ko, & Yung (2006)	Perception of doctors and nurses on the care and bereavement support for relatives of terminally ill patients in an acute setting	Discussed bereaved informal caregiver
Tunnah, Jones, & Johnstone (2012)	Stress in hospice at home nurses: a qualitative study of their experiences of their work and wellbeing. <i>International</i>	Stress with hospice nurses

(table continues)

Study, year (Reference)	Article	Rationale for Exclusion
United States Government Accountability Office (2007)	End-of-life care: Key components provided by programs in four states	Discussed governmental programs for the PACE program
Visser et al. (2004)	The end of life: informal care for dying older people and its relationship to place of death	Discussed bereaved informal caregiver
Wachterman & Sommers (2006)	The impact of gender and marital status on end-of-life care: evidence from the National Mortality Follow-Back Survey	Discussed marital status in relationship to terminally ill patients
Wentlandt et al. (2012)	Preparation for the end of life in patients with advanced cancer and association with communication with professional caregivers	Discusses patient
Zawistowski (2009)	Family and friends as caregivers	Discusses satisfaction with palliative services

## Summary

An informal caregiver for the terminally ill patient looked different from person to person. In addition, how they responded to the task of caring for their dying loved one varied from person to person and family to family. What may stress one person may come as a joy to another (Williams et al., 2011). The literature yielded information regarding their emotional, psychological, and physical characteristics. Conversely, understanding who the informal caregiver was apart from their dying loved one was not readily discovered. Gaining a clearer depiction of caregiver's characteristics would help the nursing community in providing useful information during a trying moment in their life. The following section contained the results of the integrated review of literature regarding informal caregivers apart from terminally ill patients.

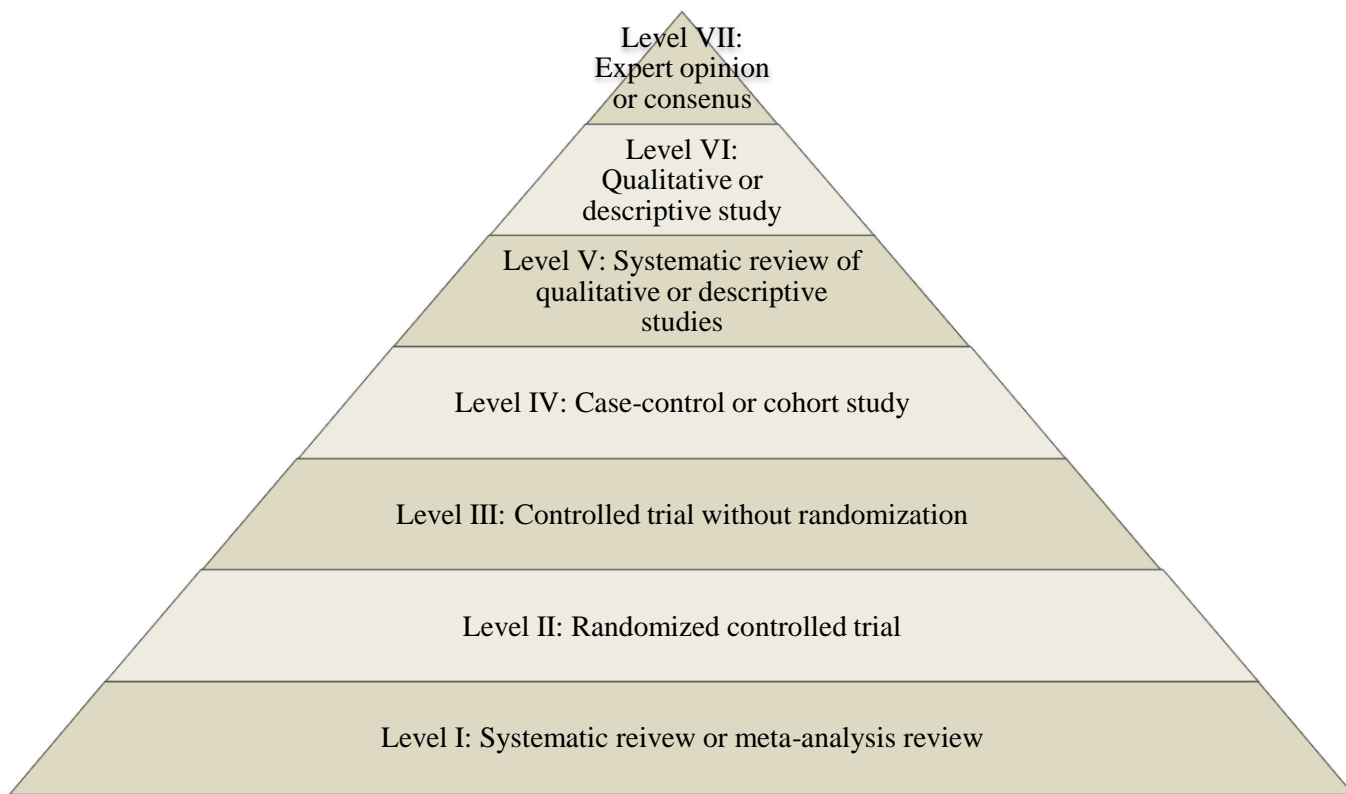
## Section 4: Findings and Recommendations

### **Introduction**

Informal caregivers are often times viewed in reference to the family member whom they take care of on a daily basis. The literature addresses the caregivers stress, anxieties, and inadequacies (Abernethy et al., 2009). The emotions that the caregiver experiences in relationship to caring for their loved one are varied. Their emotions could be stress, fear, disbelief, guilt, hopelessness, and helplessness (Mystakidou et al., 2013). However, there is a gap in the literature regarding characteristics of the informal caregiver independent of the terminally ill patient. The purpose of the DNP project was to evaluate the literature regarding the characteristics of the informal caregiver independent of the terminally ill patient or loved one. An integrative literature review was conducted in reference to the characteristics of the informal caregiver independent of the terminally ill loved one. Fineout-Overhalt et al. (2010) systematic literature review process was used to analyze the included articles (*Figure 1*).

### **Additional Exclusion**

A total of 77 articles were reviewed. Forty-four were excluded based on the exclusion criteria in Table 1. Thirty-three articles remained for further analysis. Review of the 33 remaining articles rendered an additional 11 exclusions (*Figure 2*). Upon further review, Mackenzie et al. (2007) discussed the cognitive status of the caregiver under stress while caring for terminally ill family members. Brazil et al. (2005) and Brazil, Howell, Bedard, Krueger, and Heidebrecht (2005) discussed the preferences of services and



*Figure I. Hierarchy of evidence evaluation system*

placement of care for the terminally ill patient. Washington et al. (2012), along with Schulz (2013), analyzed problem solving and research priorities for informal caregivers. Neither Zawistowski (2009) nor Nyatanga, (2012) discussed the characteristics of the informal caregiver. Krause and Kuhn (2007) along with Smith et al. (2011) discussed caregiving, however, neither study discussed caregiving in relationship to a terminally ill family member. Van Ryn et al. (2010) discussed the stressors of informal caregivers of patients who were newly diagnosed with cancer. Finally, Lin, Fee, and We (2012) study did not address caregiver's with terminally ill family members.

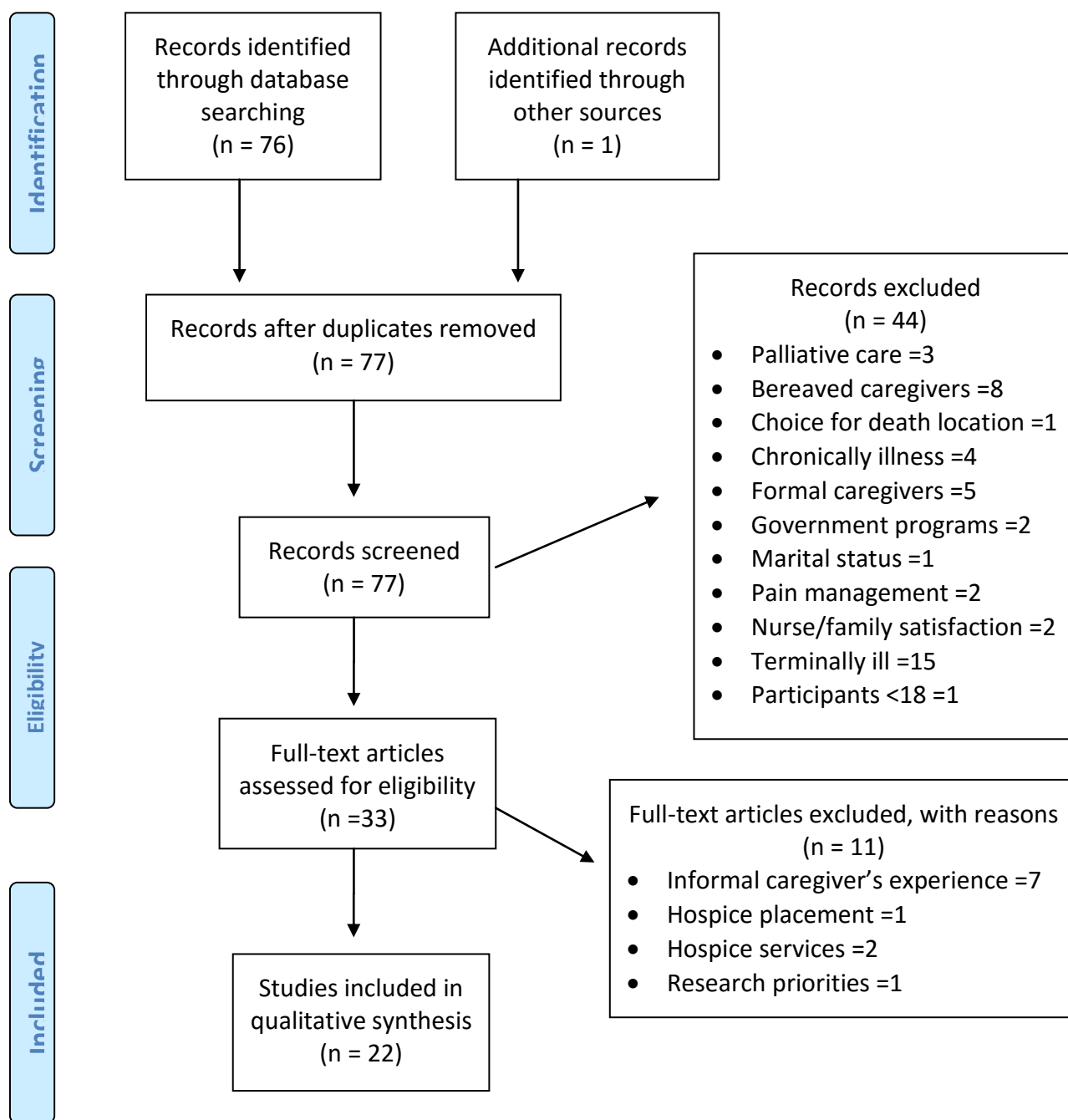


Figure 2. Inclusion Process

## **Summary Findings**

There were no Level I, II, III, or IV articles of the remaining 22 articles analyzed. There were four Level V articles, 17 Level VI articles and one Level VII article that were analyzed. Seventeen Level VI articles yield four subthemes: (a) caregiver care and support, (b) comparisons of caregiver groups, (c) communicating caregivers needs and (d) various emotional responses to caregiving. Finally, the Level VII article was an expert opinion regarding caregiver care.

## **Level V Studies**

Northfield and Nebauer (2010) completed a systematic literature review of 70 articles that reflected the caregiver's characteristics and functioning, caregiving external supports, internal supports, ongoing challenges, personal costs of caregiving and the end of the journey to caregiving. The caregiver's characteristics and functioning denoted that in western cultures, it was expected that the female, spouse or child would provide care and nurturing to the person with a cancer diagnosis. The family dynamics regarding the responsibility of the informal caregiver showed that female caregivers expressed stress and anxiety as they care for a dying loved one, maintain household responsibilities and continue to work outside of the home.

External and internal support for caregivers was found within hospice services. However, looking after one's self during the caregiver phase was extremely difficult to manage. Self-awareness, dyadic coping mechanisms and personal beliefs were paramount to coping with the burden of caregiving (Northfield & Nebauer, 2010). Managing the seasaw feelings of caregiving coupled with providing unconditional loving was difficult



to manage. Caregivers who received little emotional support often times had negative feelings regarding their role and responsibility. Whereas, those with support both emotionally and physically had more positive feelings (Northfield & Nebauer, 2010).

Bee, Barnes, and Luker (2008) completed a systematic review of 26 articles, which discussed the informal caregiver's needs in relationship to terminally ill patients at home. The purpose of the review was to assess published and unpublished evidence regarding the caregivers informational needs while caring for terminally ill people at home. The review concluded with four main themes categorized as (a) internal and external support to include the educational needs of informal caregivers, (b) potential consequences of insufficiencies in caregiver support, (c) situations that influence the informal caregiver to perform tasks, and (d) possible interventions directed at meeting the needs of the informal caregiver at home.

Evidence showed that there was a gap in knowledge regarding the provision of education for disease process and nursing care tasks (Bee, Barnes & Luker, 2008). Furthermore, there was evidence that caregivers felt that information from the professional support was inadequate or occurred too late to be helpful in their current situation. Evidence also showed that there were negative feelings and comments regarding the availability of professional support to assist the informal caregiver with practical nursing tasks and duties. Without adequate support, financially, physically, and emotionally, informal caregivers felt that their situation was out of control and difficult to manage (Bee, Barnes & Luker, 2008). Day-to-day chores and tasks were more of a burden than of empowerment to render assistance to their loved one. A number of factors

influenced the informal caregiver's ability to perform basic nursing tasks, such as the amount of care that was needed at the end of life, like turning and repositioning (Bee, Barnes, & Luker, 2008).

A woman's experience with caring for the terminally ill loved one was perceived as more stressful than that of men (Bee et al., 2008). Women were more challenged with nursing tasks such as moving and transferring patients. Education, training, and the method of information delivery to the informal caregiver were some of the potential interventions geared toward meeting the caregiver's needs. Caregivers felt that there was a great need for knowledge regarding disease progression and preparation on what to expect regarding the physical demand of the declining patient. In addition, caregivers felt that ongoing professional support would have made a difference in areas such as activities of daily living and overnight support (Bee et al., 2008).

Pinquant and Sorensen (2011) did a comparison study between, spouses, adult children, and children-in-law as caregivers of older adults. In this comparison study, the authors used a six-step meta-analysis to retrieve their data. The six-step analysis was able to categorize some differences among the three groups of caregivers, (a) spouses and adult children, (b) spouses and children-in-law and (c) children and children-in-law (Pinquant & Sorenson, 2011). There were noted differences in sociodemographics, resources, stressors, and psychological distress. The sociodemographic variables were distinguishing age differences among the group, in which there was no significant difference noted in the ages of children and children-in-law (Pinquant & Sorenson, 2011). It was also noted that spouses were more than likely to share the home of the terminally

ill patient. Whereas, the children and children-in-law were more educated, did not share the home with the terminally ill patient (Pinquart & Sorensen, 2011).

The physical health for the spouse noted to be worse than that of the children or the children-in-law. There was little difference between the informal and formal support that informal caregivers received. However, the children had a more positive relationship with the terminally ill patient. In addition, it was discovered that spouses indicated that there was lower levels of instrumental coping and effective coping than that of the children (Pinquart & Sorensen, 2011).

The differences between the caregiver groups regarding stressors were found in behavioral problems with the terminally ill patient. The spousal caregiver expressed more problems than did the adult children and the children-in-law (Pinquart & Sorensen, 2011). It was also noted that the spouse rendered more caregiving hours than that of the adult children and the children-in-law. Along with giving more caregiving hours, the spouse was also the person who gave assistance with a larger number of tasks than that of the adult children and the children-in-law (Pinquart & Sorensen, 2011).

Finally, the psychological distress was found to be high among spouses in relationship to physical burden and relationship strain. The study also showed that there was more financial strain and depression among the spouse than the adult children and children-in-law. As expected, children expressed feelings of depression at a greater level than that of the children-in-law (Pinquart & Sorensen, 2011).

Kovacs, Bellin, and Fauri (2006) conducted a peer review of articles related to the merging of clinicians (formal caregivers) involving the inclusion of families during the

end-of-life care. The authors did not include the number of articles that were reviewed. However, their focus was on the Family-Centered Care model (FCC). This approach to hospice and palliative care focuses on the advantageous partnerships between the clinicians, patients and their families. There were four tenets to the FCC (a) all people were to be treated with dignity and respect, (b) health clinicians were to communicate fully and completely with families and patients without bias in a manner that is encouraging, (c) patients with their family members were to build their strength through participating in useful experience that focused on control and independence, and (d) there was collaboration between health clinicians, patients and family members in relationship to policy and program development, delivery of care to the patients as well as for professional education.

Kovacs, Bellin, and Fauri's (2006) study was divided into three major areas: (a) family-centered care at the end of life; (b) barrier to family-centered care at the end of life; and (c) caring for others. The authors discovered that family involvement at the end of life was very important to the families. Some of the barriers to family-centered care were centered around family members perception of the lack of psychosocial support as well as power struggles between the providers and the family and poor communication. The authors concluded that finding support for the caregiver was challenging and demanding. It was also suggested that developing a family centered care at the end of life model, may help to alleviate some of the stressors and allow the family to enjoy the terminally ill loved one's final days (Kovacs et al., 2006).

**Level V Summary.** Two out of four articles were literature reviews, one article

was a systematic review and the fourth article was peer-reviewed (Table 2). Northfield and Nebauer (2010) concluded that there was little research found on the coping strategies utilized by informal caregivers at various stages of the terminal illness. The Table 2.

*Summary of Level V Studies*

<b>Summary of Level V Studies</b>			
<b>Author</b>	<b>Type of Study</b>	<b>Sample Size</b>	<b>Sample Demographics</b>
Northfield & Nebauer (2010)	Literature review	70 articles	Articles grouped into three categories in relationship to informal caregiver's characteristics and functioning, support systems (external & internal), challenges while caring, costs of caring and coping while supporting their terminally ill loved one.
Bee, Barnes, & Luker, (2008)	Systematic review	26 studies	Articles that evaluated informal caregivers' needs
Pinquart & Duberstein, (2005)	Literature review	168 empirical studies	Articles that included spouse caregivers compared with adult children/in-laws or child caregiver compared to children-in-law
Kovacs, Bellin, & Fauri (2006)	Peer-reviewed	n/a	Articles regarding hospice and palliative care; family-centered care models; caregiver literature

authors also concluded that the role and responsibility of being a caregiver was overwhelming, physically demanding and emotionally draining. Pinquart and Sorensen's (2011) analysis of the literature specifically reviewed articles related to three groups of people, spouse, adult children/children-in-law and children caregiver. These three groups

were compared against each other regarding sociodemographics, resource, stressors and psychological distress. Bee et al.'s (2008) systematic review suggested that home hospice services were ineffectively focused on helping informal caregivers obtain practical nursing skills. Kovacs et al. (2006) discussed peer-reviewed articles as a resource in end-of-life and palliative care for social workers. The focus of this article was not geared towards nursing. However, it did discuss an important aspect regarding caring for the caregiver while they care for their terminally ill loved one.

Bettany-Satltikov (2012) explained the traditional literature review as a story that the reviewer wanted their audience to know. The literature review often times did not follow a prescribed scientific review of the literature, therefore some articles included would be bias and haphazardly used. Polit and Beck (2014) described integrated or systematic literature review as the basis of evidence based practice. However, Grove, Burns, and Gray (2013) revealed that there were biases in conducting a systematic review. Publication, time lag, location and duplication were listed as some biases related to a systematic review.

### **Level VI Studies**

*Caregiver care and support.* Waldrop et al. (2005) conducted qualitative in-depth interviews with 74 caregivers of informal caregivers of terminally ill patients that had been receiving hospice care for two or more weeks. The caregiver's ages ranged from 21 to 87, while the terminally ill patient's age range was 54 to 88 years of age. The majority of the caregivers were either a spouse (46%) or an adult child (49%) (Waldrop et al., 2005). The remaining caregivers were siblings and a grandchild. Ninety-two percent (n =

68) of the participants were Caucasian, while five were African American and one was Hispanic (Waldrop et al., 2005).

The study utilized family caregiving career as its conceptual framework and the stress process model as the theoretical framework. The results from the in-depth interviews were divided into broad subthemes, transition to end-stage caregiving and end-stage caregiving and the stress process model (Waldrop et al., 2005). In the transition to end-stage caregiving, the receiving information regarding the terminally ill's current diagnosis and status was understood and known. The families had an expectation that information regarding the patient's prognosis and expected progression would be delivered by physicians, social services and other health care providers. The informal caregiver's understanding of the terminally ill loved one's status also included observation of their physical decline, personality change and role loss. Caregiver's expressed a sense of loss, long before the patient's more obvious changes (Waldrop et al., 2005).

The end-stage caregiving and the stress process model revealed primary stressors such as caregiving tasks, that included hands on care and managing the loved one's change in the transition process (Waldrop et al., 2005). It also revealed secondary stressors in relationship to family role conflict, work conflict and financial stress. The in-depth interview also revealed various positive and negative outcomes, such as meaning making and psychological and emotional distress. Finally, the informal caregiver experienced support from their association with their religious affiliations and practices (Waldrop et al., 2005).

Epiphaniou et al. (2012) conducted a one-to-one qualitative study with 20 informal caregivers of terminally ill patients living at home. The authors captured informal caregivers methods of handling the care and responsibility of a terminally ill loved one into two categories, coping and support (Epiphaniou et., 2012). Some informal caregivers coped by using distractions, such as watching television or completing a crossword puzzle (Epiphaniou et al., 2012). While others managed their stress by channeling feelings towards the positive aspect of caregiving and not the negative. The focus of the support was mostly related to the support received from clinicians, family and friends. Informal caregivers expressed great relief from the support received from formal caregivers such as the hospice nurse and the physicians (Epiphaniou et al., 2012).

Empeno et al. (2011) conducted a hospice caregiver support project which offered informal caregivers support and services that was not covered by hospice. Pearlin's role overload measure (ROM) was used to compare respite benefits before and after the project began. The ROM was a four-item measuring score for caregiver stress. Based on the information collected, the authors enrolled 182 participants in the study and offered them extended services (Empeno et al., 2011). The results were divided into three themes, services, hospice respite benefit, and stress reduction. The majority of the recipients received care and services related to areas such as activities of daily living and patient care. During the study period there was a decrease use of hospice respite benefits. Conversely, there was a significant decrease in the Pearlin's ROM after the use of the added services. The follow-up assessment revealed an overwhelming positive response to the added services for the informal caregiver.



Williams et al. (2011) conducted a study of 57 informal caregivers regarding Canada's Compassionate Care Benefit (CCB) through telephone interviews. The study evaluated the strengths and weaknesses of CCB. The CCB is a federally funded program in which eligible employees may take temporary secured absence from work in order to care for the physical, emotional, psychological needs of a terminally ill loved one, as well as to coordinate their care and services (Williams et al., 2011). The participants indicated that providing intense care for their loved one caused a great deal of stress related to the ability to negotiate leave from work and managing the monetary costs in association with caring for their loved one. The participants also concluded that the experience of caring for their loved one had a negative impact in their lives. During caregiving, the participants had feelings of anxiety, loss of sleep, depression, fatigue, and physical ailments (Williams et al., 2011).

Caregivers expressed mixed feelings in relationship to the support they received from the health and social services in their areas (Williams et al., 2011). Some were grateful; while others expressed, the inadequacies of the health services, which in turned caused them a great deal of stress. Many of the participants expressed satisfaction with the support that they received from family and friends. However, some participants indicated that they had a difficult time sharing the care burden with those who were close to them (Williams et al., 2011).

*Comparisons of caregiver groups.* Abernethy, Burns, Wheeler, and Currow (2009) conducted a health survey in Australia of 15,085 of persons who were informal caregivers fulltime, occasionally or intermittently. Women were overwhelming the

primary caregiver. The authors discovered that financial burden depended on the intensity of the care provided. A small minority of the daily caregivers and the intermittent caregivers (9.2% and 6.0%, respectfully) had a severe financial impact on their household (Abernethy et al., 2009).

Abernethy et al. (2009) compared the daily hands on caregiver to the intermittent hands on caregiver. The daily hands-on caregiver was a spouse, partner, child or parent. Whereas, the intermittent hands-on caregiver was either a child, parent, other relative or friend. Nearly more than half of those who provide daily care had an annual income of less than \$28,000 (Aberneth et al., 2009). Whereas, the income for intermediate hands on averaged \$42,600 (Aberneth et al., 2009).

Brazil, Thabane, Foster, and Bedard (2009) analyzed the differences between in spousal caregiving at the end of life. The primary focus of this study was to examine the differences between men and women informal caregivers at the end of life of their terminal loved one. The study included a total of 283 persons of which the vast majority of them were women. Through an indepth telephone interview, three themes in gender differences emerged: (a) amount of caregiving and caregiver strain; (b) services used and needed; and (c) example of support to the terminally ill patient (Brazil et al., 2009). Women reported considerably, more than men, that they felt a high level of caregiver strain. Women also reported the use of transportation services more than men. While, men significantly reported a higher use of consultants for pain and symptom management. Women often provided more support than men in relationship to activities of daily living (Brazil et al., 2009).

Williams, Wang, and Kitchen (2014) analyzed whether or not there was a difference between end-of-life, long-term care and short-term care caregivers providing informal care services. Services were given at the informal caregiver's home, the recipient's home or somewhere else in the community. Characteristics of caregivers were in relationship to sociodemographics such as age, gender, marital status, income, etc. The majority of the caregivers were married women in all three characteristic groups (Williams et al., 2014). Nearly half of the informal caregivers had more one or more chronic diagnoses. Impacts of caregiving and determinants of the impacts of caregiving were also identified.

End-of-life caregivers, more often than not, reduced their social activity in things such as holiday parties and gatherings. Overall, all three caregiver groups significantly decreased their socialization with their friends and family (Williams et al., 2014). End-of-life caregivers exhibited greater financial strain and burden than the short-term and long-term caregivers. The impact of caregiving effected the end-of-life caregivers more than the other two caregiver groups. Although the end-of-life caregivers had the more financial strain, they were also the ones who had access to monies from governmental agencies (Williams et al., 2014).

Brazil, Kaasalainen, Williams, and Rodriguez (2013) conducted a study comparing the experiences between rural and urban informal caregivers. The study was a cross-sectional telephone based survey which assessed (a) perceived caregiver burden, (b) perceived social support and (c) functional status of the terminally ill patient (Brazil et al., 2013). Rural caregivers utilized the resources of hospital services more than urban

caregivers. Whereas, urban caregivers used respite services more frequently. There was no difference between the two groups regarding caregiver burden. Each group discribed high levels of support from family and friends.

*Communicating caregivers need.* Bachner and Carmel (2009) performed a study assessing open communication with informal caregivers regarding the terminal illness and diagnosis of their loved one. The authors assessed their open communication in two areas, the characteristics of the caregiver and the situational variables. The caregiver's characteristics were sociodemographic in nature. Such areas as relationship to the patient, age, gender, eduction, religion and employment status were assessed. The authors discovered that open communication between the informal caregiver and the terminally ill loved one was low (Bachner & Carmel, 2009). This low level indicated that there was a significant communication deficits between them. The situational variables were idenitified as length of caregiving, number of hours care was provided daily, the level of perceived loved one's physical and emotional suffering and general function. During the authors analysis, they determined that the longer the informal caregiver managed the activities of daily living for the terminally ill, the more open communication occurred (Bachner & Carmel, 2009). It was thought that the longer care was provided the more the informal caregiver acknowledged that the end was nearing. Therefore, it allowed for better communication about what was imminent.

Information needs of the informal caregiver was examimed by Fukui (2004). The author investigated disease related and care related information needs for the informal caregiver. The author also assessed the sociodemographics in relationship to the informal

caregiver's informational needs. Among the 66 informal caregivers that were interviewed, the majority of them wanted more disease-related and care-related information. The length of stay in the palliative care unit played a major role into how much disease-related and care-related information the informal caregiver wanted to receive. However, nearly one-third of the informal caregivers did not want to know the prognosis of their loved one (Fukui, 2004). It was suspected that this was due to avoidance in order to cope and manage with the terminal diagnosis.

*Various emotional responses to caregiving.* Emanuel et al. (2008) conducted a study of informal caregivers in Uganda regarding challenges they faced while providing care to a terminally ill patient. Sixty-two face-to-face interviews were completed. The vast majority of those providing care were family related. The study concluded that the majority of the interviewees were in need of financial assistance, medical assistance, additional income and caregiver training (Emanuel et al., 2008). The care provided to the terminal ill included activities of daily living, household chores, spiritual and financial support, and transportation assistance. Overwhelmingly, the majority of those interviewed indicated that they would strongly consider hiring someone to assist them. In addition, nearly 95% of the interviewees indicated that caregiver training would be extremely helpful and would want to become certified caregivers (Emanuel et al., 2008).

Townsend et al. (2010) completed a study that assessed informal caregivers strain regarding their physical, emotional, social, economic, and spiritual wellbeing in relationship to caring for their terminally ill loved one. The authors completed an indepth interview of informal caregivers responsible for terminally ill persons over 65 (Townsend

et al., 2010). The sociodemographics were assessed and found that the majority of the those who participated were Caucasian women who were either spouses or adult children or children-in-law. The authors discovered that there was no difference found in any of the five previously listed strains for gender or length of caregiving (Townsend et al., 2010). However, there was a higher level of strain among the younger informal caregivers. Informal caregivers that cared for loved ones with cancer, expressed a lower level of strain regarding psychological, physical and social strain. The authors discovered that younger caregivers and caregiver's health had higher cumulative strain.

Grant et al. (2013) completed an in-depth study with 163 informal caregivers of persons with non-small-cell lung cancer in Southern California. The purpose of this study was to analyze and evaluate caregivers' burden, quality of life and skills preparedness. This study was limited to only persons who were responsible for managing care of patients with non-small-cell lung cancer. The characteristics of the informal caregivers was in relationship to their sociodemographic status. Areas captured were age, gender, employment status, highest education level achieved, and marital status. As seen in the previous studies, the majority of the caregivers were female. Subjective stress experience was high. Whereas, objective burden changed over time, where it initially peaked, then dropped significantly. At onset, caregivers perceived that their skills preparedness was high. However, over time, their perception of their skills significantly changed. The quality of life of the informal caregiver was initially high at baseline, but significantly decreased over time (Grant et al., 2013).

Mystakidou et al. (2013) investigated the relationship between the informal caregiver's anxiety while providing care to the terminally ill and self-efficacy along with their sociodemographic characteristics and what role these variables played in their self-efficacy. Among the 107 informal caregivers which were interviewed, it was discovered that the single most problem identified was the effect of the terminal illness on the entire family (Mystakidou et al., 2013). Anxiety in the caregivers could be associated to their concerns of the unknown, related to death, fear of loss, loneliness and the responsibility of those left behind, such as children. These stressors could influence how they care for the terminally ill loved one. Spouses were noted to have a high-risk of psychiatric disorders, especially in patients with terminal cancer. It should be noted that women were more likely to decrease their work hours and experience excess stress and role disruption. Women were also found to have an increased amount of emotional distress secondary to their role and responsibility as a spouse and caregiver. The authors discovered that family members focused more on the terminal patient therefore not offering much support to the informal caregiver (Mystakidou et al., 2013). These actions left the informal caregiver with feelings of inattention and neglect.

Kulkarni et al. (2014) conducted a study of 137 informal caregivers regarding their level of stress in relationship to caring for their terminally ill loved one. The sociodemographic characteristics were analyzed. The authors assessed the informal caregivers age, employment status, gender, relationship status and education. The majority of the participants were women and were spouses to the terminally ill patient.

The majority of the 137 informal caregivers had a positive perception providing care (Kulkarni et al., 2014). However, there were a significant number of caregivers who felt trapped in giving care based on their relationship to the terminally ill loved one. Family support among the caregivers were extremely helpful during a difficult time. Stress among the caregivers were noted. Seventy-four of the informal caregivers would consider asking for outside help. Whereas, 45 caregivers were dependent on other family members to assist (Kulkarni et al., 2014). The social impact of the caregivers was not a major factor. Most felt that their personal and private life was not lost. Exhaustion, tiredness, insomnia, lack of focus, and mental confusion were significantly high for the participants (Kulkarni et al., 2014).

Bainbridge et al. (2009) conducted an indepth study utilizing the Stress Process Model (Pearlin, 1989) examining stress predictors of informal caregivers who provided care to their terminally ill loved one. The sociodemographic areas that were analyzed were age, gender, relationship, income, number of hours care was provided, and educational acheivements. The majority of the informal caregivers were women who were married to the terminally ill patient.

The study discovered that the informal caregiver's high perception of program accessibility and functional social support did not predict a high level of stress or strain (Bainbridge et al., 2009). The caregivers with poorer health and who were younger in age showed a high prediction of stress. Conversely, the study also found that the informal caregiver's job, family structure/dynamic or relationship to the terminally ill patient did not contribute to increased caregiver strain (Bainbridge et al., 2009).



Dumont et al. (2006) examined how the extent of the informal caregiver's psychosocial distress was influenced by the terminally ill patient's performance status. The authors assessed 212 informal caregivers regarding services, care provided, caregiver's characteristics, and the level of psychological distress. The sociodemographic characteristics assessed were gender, relationship to the terminally ill patient, living arrangements, marital status, age, psychological support, and education level (Dumont et al., 2006).

The study revealed that increased stress occurred when the patient's independence decreased (Dumont et al., 2006). Also noted was the increase in depression, anxiety and cognitive distress. Conversely, pain, dyspnea, gastrointestinal disturbance, and confusion of the terminally ill patient was not associated with caregiver distress. The authors also discovered that younger caregivers experienced more psychological distress than older caregivers. Finally, the caregivers distress increased when the terminally ill loved one was confined to a bed the majority of the time (Dumont et al., 2006).

***Level VI Summary.*** There were 17 Level VI articles reviewed (Table 3). These articles were divided into four subthemes: (a) caregiver care and support; (b) comparisons of caregivers groups; (c) communicating caregiver needs; and (d) emotional responses to caregiving. Caregiver care and support articles discussed various levels of support received by the informal caregiver during their time caring for their loved ones. Williams et al. (2011) revealed that some caregivers found it rewarding to care for their loved ones and received a great deal of support from their family and community resources. Whereas Waldrop et al. (2005) discussed the many stressors associated with caring for a dying

loved one. Epiphaniou et al. (2012) and Empeno et al. (2011) discussed the importance of providing support to the informal caregiver.

Table 3.

*Summary of Level VI Studies*

<b>Summary of Level VI Studies</b>		
<b>Author</b>	<b>Sample Size</b>	<b>Sample Demographics</b>
Waldrop et al. (2005)	74 informal caregivers	Family members on hospice for min. 2 weeks
Epiphaniou et al. (2012)	20 informal caregivers	Caregivers >18 yrs old; main caregiver;
Empeno, Raming, Irwin, Nelesen, & Lloyd (2011)	123 informal caregivers	Caregivers identified as needing additional support
Williams et al. (2011)	57 informal caregivers	Compassionate Care Benefits applicants (approved & denied); those who never applied
Abernethy, et al. (2009)	15,085 caregivers	Caregivers who annually participated in Australia's Health Omnibus Survey; interviews conducted with person who cared for terminally ill persons
Brazil, Thabane, Foster, & Bedard (2009)	283 informal spousal caregivers	Spouses of terminally ill loved ones
Williams, Wang, & Kitchen (2014)	471 informal caregivers	Informal caregivers who had been caring for a terminally ill person for > 2 years
Brazil, et al. (2013)	100 informal caregivers	Participants who lived in rural and urban areas who cared for a terminally ill person
Bachner & Carmel (2009)	236 caregivers	Primary caregivers for terminally ill cancer patients
Fukui (2004)	66 caregivers	Japanese caregivers of institutionalized patients on a palliative care unit
Emanuel et al. (2008)	62 informal caregivers	Ugandan caregivers caring for a terminally ill loved one
Townsend et al. (2010)	162 caregivers	Caregivers who provided care to patients >65+ yrs old who were on hospice; caregivers who were > 18 yrs old

(table continues)

<b>Author</b>	<b>Sample Size</b>	<b>Sample Demographics</b>
Grant et al. (2013)	163 family/friends	Caregivers of non-small-cell lung cancer patients > 18 yrs old
Mystakidou et al. (2013)	107 caregivers	Greek caregivers who cared for persons with terminal cancer
Kulkarni et al. (2014)	137 participants	Informal caregivers who cared for patients at Cipla Palliative Care Center
Bainbridge et al. (2009)	132 family caregivers	English speaking; primary caregiver for persons >50 yrs of age in urban and rural areas
Dumont et al. (2006)	212 family caregivers	Caregivers who cared for persons with terminal cancer

Comparisons of caregiver groups section provided a compare and contrast between various types of caregivers or types of care that was provided. Brazil et al. (2009), Brazil et al. (2013) and Williams, Wang, and Kitchen (2014) compared differences between the different types of caregivers, spouses verses children or urban caregivers verse rural caregivers. Whereas, Abernethy et al. (2009) discussed the various levels of end-of-life care provided by the informal caregivers.

Bachner and Carmel (2009) and Fukui (2004) discussed communicating the caregivers needs. Fukui (2004) utilized a likert scale to assess the needs of Japanese family caregivers of terminally ill loved ones who suffered with cancer. The author discovered that there was an increase need for disease-related information for the caregivers. Bachner and Carmel (2009) conducted a structured interview with prescribed questions for the terminally ill loved one regarding their communication with their terminally ill loved one in their final days.

The emotional responses from informal caregivers were vast. Emotions range from anxiety (Mystakidou et al., 2013), caregiver burden (Grant et al., 2013), and

psychological distress (Dumont et al., 2006). Kulkarni et al. (2014) and Bainbridge et al. (2009) discussed how informal caregivers exhibit poor health during the time that they care for their terminally ill loved one. Townsend et al. (2010) discovered that caregivers struggled with making plans for outside activities because of their loved one's terminal illness.

There were significant limitations to the literature reviewed for Level VI. Notably, Emanuel et al. (2008) expressed limitations in relationship to language and cultural barriers with the Ugandan people. Grant et al. (2013) indicated that their study's limitations were in relationship to including caregivers who cared for terminally ill patients at various stages of nonsmall-cell lung cancer. Townsend et al. (2010) discovered that their limitations were because their study only included informal caregivers who were over age 65 and underrepresented minority participants of hospice services. Dumont et al. (2006) and Mystakidou et al. (2013) concluded that the limitations to their studies were in relationship to the underrepresentation of the psychosocial distress with the informal caregiver. Finally, Bainbridge et al. (2009) and Kulkarni et al. (2014) indicated their studies failed to adhere to the questionnaire as designed therefore causing potential bias.

#### **Level VII Study.**

Collins and Swartz (2011) identified that primary care physicians were in a great position to perform caregiver assessments to identify high levels of caregiver burdens. They identified caregiver burden included health effects, financial burden and inadequate preparation. During the care of their loved ones, caregivers had fallen ill themselves,

which in turn, increased the feelings of failure and inadequacy. The financial burden was greater on the female than it was on the male. Women caregivers who provide care and services for their dying parent are more than twice as likely than a non-caregiver to live below the national poverty line (Collins & Swartz, 2011). Too often, informal caregivers felt they were inadequately and insufficiently trained in the skills necessary to care for their dying loved one. Self-management, decision support, and communication systems were identified as important tools to assist the caregiver.

***Level VII Summary.*** Collins and Swartz (2011) study was at the lowest level of appraisal, authoritative review or opinion. This study did not include a sample size or description of any type of sample. Instead, the authors gave their opinion regarding caregiver care. It also discussed how physicians could assist in obtaining information to identify informal caregivers who were in need of assistance. The authors gave a description of a caregiver assessment tool to assist in obtaining that information, however, the tool was not readily available to the public and permission was not given to publish with a third party.

### **Implications**

The implications for this DNP project are two-fold, in relationship to the informal caregiver and to the nursing community. First, the findings in relationship to the informal caregiver are associated with their sociodemographic characteristics. The sociodemographics primarily assessed were age, relationship status, financial status, and educational status. These areas were used to ascertain statistics of those who were interviewed or analyzed. Second, the findings did not focus on who the informal

caregiver was without assessing their relationship to the terminally patient and or loved one. The informal caregivers' relationship assessed in conjunction with the terminally ill patient/loved were related to stress, anxiety, caregiver burden, and financial burden. One was unable to discern who the informal caregiver was without evaluating their relationship to the terminally ill.

The nursing community should not ignore the characteristics of the informal caregiver. Understanding whom the informal caregiver is apart from the terminally ill patient will support the nursing community in their holistic approach to caring for the terminally ill patients. A holistic approach to care for a patient should include the informal caregiver. Therefore, the implications for the nursing community are to embrace the informal caregiver by getting to know them personally and individually. It is also an opportunity to address a holistic plan of care that includes the terminally ill loved one and the informal caregiver. Creating a plan of care that inclusive and not exclusive will foster a better relationship between the informal caregivers, the terminally ill patients and the nursing community.

### **Recommendations**

The recommendation to bridge the gap in the literature is to conduct a study that would identify the characteristics of the informal caregiver, which not only addresses the sociodemographic information but other characteristics as well. Another recommendation is for the nursing community, upon admission to the facility or the services, conduct an informal caregiver assessment that would include questions that solely pertained to the informal caregiver. A questionnaire would include a psychosocial, spiritual, and health

assessment of the informal caregiver. The information gathered, in conjunction with the patient's plan of care, will assist in devising a holistic plan of care.

A mixed-method research is recommended to assist in narrowing the gap of understanding the characteristics of the informal caregiver. A mixed-method research is considered when the author collects both qualitative and quantitative data to be analyzed (Grove et al., 2013; Polit & Beck, 2014). Capturing phenomena is complex. Utilizing mixed-method research the author is more likely to summarize the quintessence of the phenomenon (Grove et al., 2013).

Changing the focus of nursing staff from strictly patient-focus to a holistic approach to include the family is essential. The nursing staff, particularly in long-term care or hospice, will need training on how to manage family dynamics in relationship to the characteristics of the informal caregiver. Educating staff on the various types of characteristics will assist them when confronted with a family member who has misdirected their anger towards the staff. The education of the staff can occur in one setting. However, a series of sessions to include role-play would be beneficial in aiding the staff during difficult times interacting with family members.

### **Strengths and Limitations of the Project**

One strength of this integrative systematic review includes the ability to review literature from different disciplines such as social services; thereby broadening the viewpoint to be inclusive of multiple disciplines. One limitation was the inability to conduct actual interviews with informal caregivers. Conducting interviews with a large number of informal caregivers could lead to developing a more precise list of individual

characteristics of the informal caregiver. This information could then lead to a more accurate description of the characteristics of the informal caregiver. Another limitation identified was that there were very few Level V articles; therefore, reemphasizing the lack of prescribed scientific review of the literature (Fineout-Overhalt, et al., 2010).

### **Summary**

Informal caregivers of the terminally ill should not be ignored. Who they are independent of the terminally ill patient/loved one is vital to understanding the patient as a whole, including those that care for them. The gap in literature of what the characteristics of the informal caregiver are makes it difficult to identify the possible needs that they may have. Therefore, the inability to identify their needs could negatively affect their overall well-being and have a negative impact on the care and services the terminally ill loved one may receive. Educating the nursing community on how to manage the terminally ill and their informal caregiver is essential to meeting the needs of both the family and the terminally ill patient. The integrative systematic literature review suggests that the identification or description of the characteristics of the informal caregiver is lacking and needs to be explored in order to decrease the gap in a holistic approach to patient care.



## Section 5: Dissemination Plan

### **Dissemination Plan**

There is a gap with understanding what the characteristics of the informal caregiver. The integrative literature discovered that there were many descriptions of the informal caregiver (Empeno et al., 2011; Epiphaniou et al., 2012; Waldrop et al., 2005; Williams et al., 2011). However, they were in relationship to the terminally ill patient. Educating the bedside nurse along with nursing administration is paramount to understanding the characteristics of the informal caregiver apart from their relationship to the terminally ill patient.

After graduation, I plan to collaborate with area hospice facilities and or agencies and long term care facilities in order to disseminate this project. The rationale for targeting the bedside nurse is because he or she is usually the first person the informal caregiver encounters in the admission process. The nurse needs to learn how to incorporate what they learn from the informal caregiver into the holistic care of the terminally ill patient. It is also important to target the administrative nursing team. The administrative team is responsible for the ongoing education of the nursing department (registered nurses, licensed practical nurses, certified nursing assistants, and home health aides). Involving all nursing disciplines in the plan of care will increase continuity and consistency in delivering care to holistically to the terminally ill patient, while giving the necessary support to the informal caregiver.

Also upon graduation, I will seek authorization to offer this DNP project for continuing education units for live attendance, as well as for publication in journals such

as International Journal of Palliative Nursing, Journal of Clinical Nursing and Health and Social Care in the Community. Publication in these journals would generate multiple health providers to consider alternative ways to increase the involvement of the informal caregiver in the plan of care.

### **Analysis of Self**

This integrated literature review provided me an opportunity to shed light on a group of people who are often ignored and dismissed in relationship to the terminally ill patient. Conducting this project also provided an opportunity to generate conversations within the nursing community on the importance of understanding the characteristics of the informal caregiver independent of their relationship to the terminally ill patient. In addition, this project helped to validate my feelings and experiences in relationship to being an informal caregiver to my uncle several years ago.

As a former DON of a nursing home, too often I experienced an angry and frustrated family member who wanted the best for their dying loved one. While I was in the midst of managing the nursing staff, it was difficult to always clearly identify the needs of the informal caregiver. It was not until I found myself being an informal caregiver that I truly understood the frustration that others were experiencing. Researching the literature helped me to discover that there was a gap in the literature regarding the needs of the informal caregiver from a nursing perspective.

Developing this DNP project from inception has helped me to become more skilled in searching the literature as well as analyzing the literature regarding my subject matter. Honing in my skills of searching, analyzing and synthesizing the literature will

assist me in my future endeavors as a professor, mentor of nursing students and colleagues.

### **Summary**

Discovering the characteristics of the informal caregiver independent of the terminally ill is important to increase communication between the nursing community and the informal caregiver. Along with increasing communication, it also assists in incorporating informal caregivers in a holistic approach to the plan of care for the terminally ill patient. The gap in literature could be bridged by developing an informal caregiver assessment form and by increasing education to the nursing community.

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# Characteristics of Informal Caregivers: An Integrative Review

JONANNA R. BRYANT MSN, MS, RN

DNP DOCTORAL PROJECT, SECOND ORAL DEFENSE

## Background

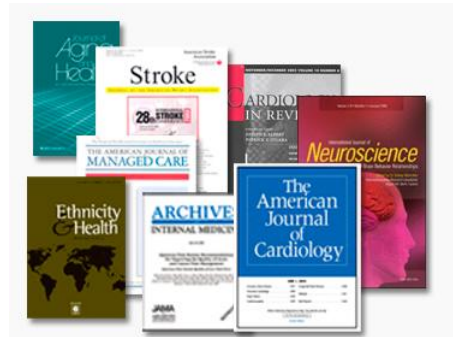
- 36 million adults provide care to someone over age 65 (National Alliance for Caregiving, 2009)
- Pennsylvania is ranked 4<sup>th</sup> for population >65 (Choosing a nursing home, n.d.)
- As of March 2009 >81,000 Pennsylvanians were placed in nursing homes (Choosing a nursing home, n.d.)



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➤ Literature discusses the following in relationship of the caregiver and the terminally ill patient

- ❖ Caregiver burnout
- ❖ Stress
- ❖ Feelings of the primary caregiver with dementia
  - Anxiety, depression, emotional stress, isolation, hopelessness and helplessness



## Problem Statement

Informal caregivers of the terminally ill are faced with a myriad of feelings and responsibilities.



## Problem Statement

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Informal caregivers of the terminally ill are faced with a myriad of feelings and responsibilities.



## Purpose Statement

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Purpose: To assist the nursing community in identifying characteristics of the informal caregiver independent of the terminally ill patient through an integrative literature review.



## Research Question

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What are the characteristics of the informal caregiver, independent of the terminally ill loved one?



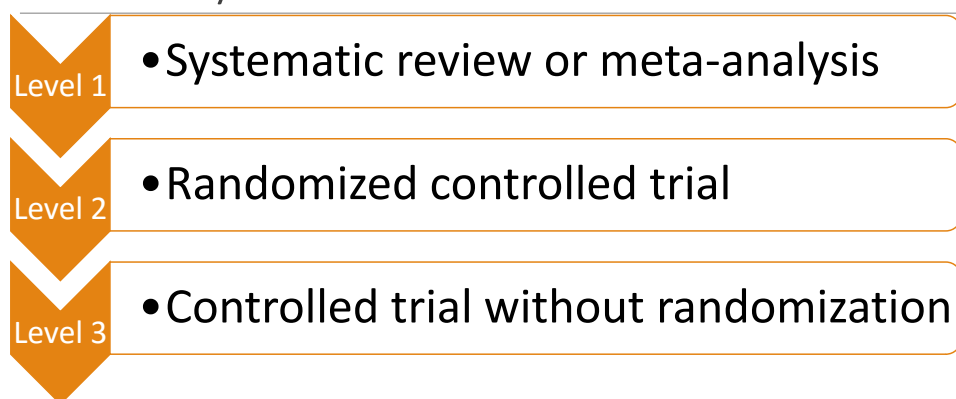
## Theoretical Framework

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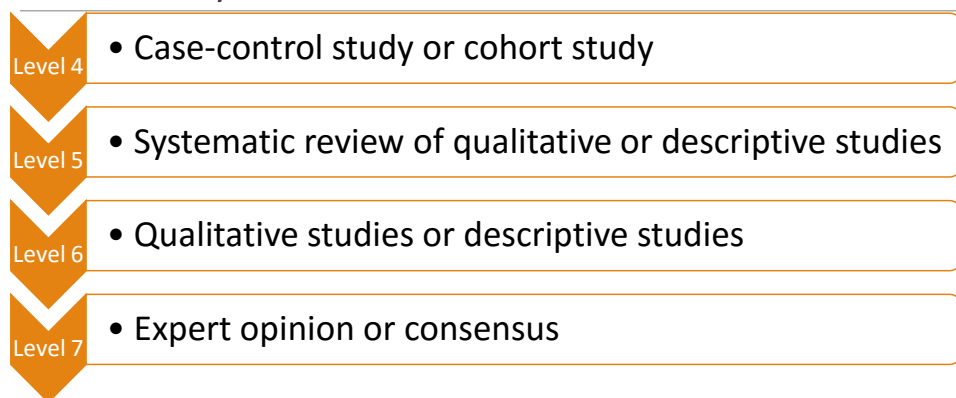
Fineout-Overhalt, Melnyk, Stillwell  
& Williamson's Hierarchy of Evidence



## Hierarchy of Evidence



## Hierarchy of Evidence





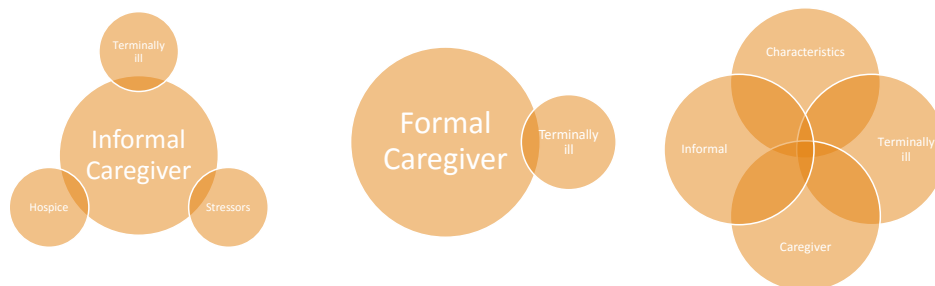


## Data Collection

- CINAHL
- MEDLINE
- MEDLINE with full text
- Academic Search Complete
- PsychArticles
- ERIC
- SocIndex with full text
- PsychINFO



## Search Strings



## Data Analysis

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Critical Appraisal Guide



## Critical Appraisal Guide

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1

Why was the study done?

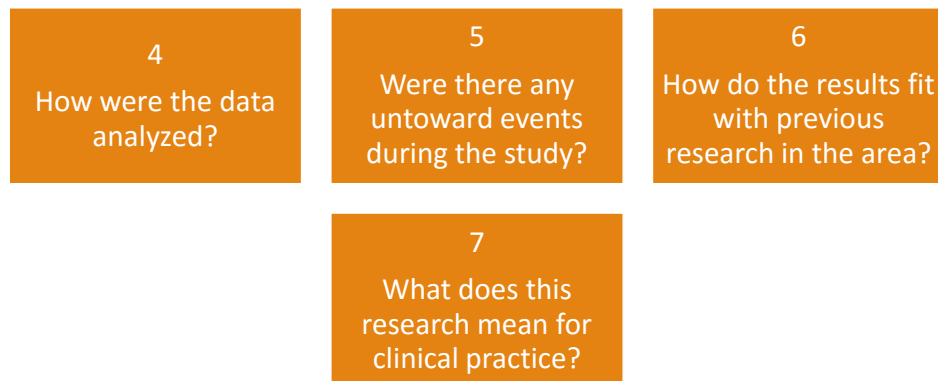
2

What is the sample size?

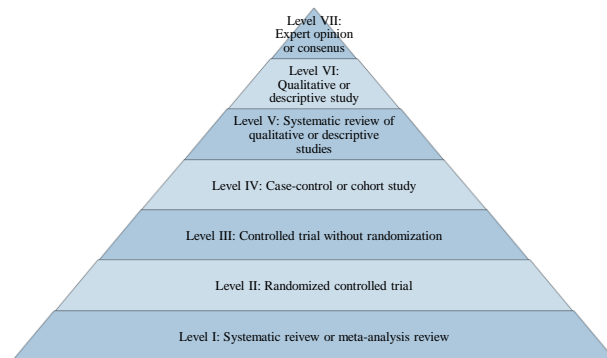
3

Are the instruments of the major variables valid and reliable?

## Critical Appraisal Guide



## Findings

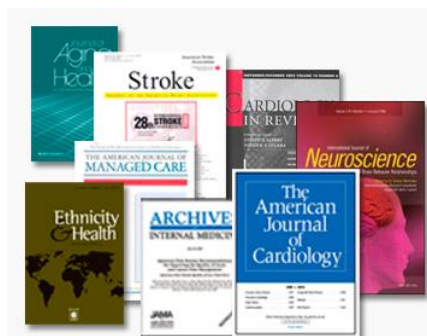


## Level V Studies

- Literature Reviews
  - ❖ Little research found regarding coping strategies used by informal caregivers
  - ❖ Role & responsibility of caregiving: overwhelming, demanding & draining
  - Spouses, adult children/children-in-law & Children caregivers were compared
    - ❖ Compared sociodemographics, resources, Stressors & psychological distress



- Systematic Review
  - ❖ Home hospice services were ineffectively Focused on helping informal caregivers Obtain practical nursing skills
- Peer-reviewed
  - ❖ Not focused on nursing, but social workers
  - ❖ Emphasized caring for the caregiver



## Level VI Studies

### ➤ Caregiver Care and Support

- ❖ Informal caregivers expected communication from health providers
- ❖ Informal caregiver experienced support from religious affiliations
- ❖ Informal caregivers coped by using distractions
- ❖ Informal caregivers channeled positive feelings
- ❖ Informal caregivers expressed relief when they providers



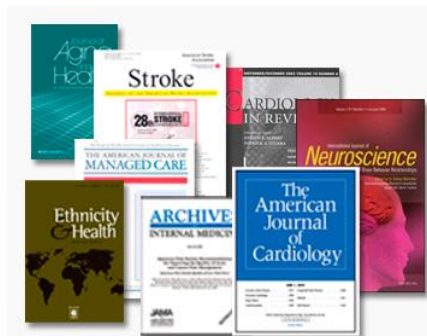
### ➤ Caregiver Care and Support, cont'd

- ❖ Positive responses from informal caregivers when additional support was received from hospice agency
- ❖ Informal caregivers expressed satisfaction when they received support from family and friends
- ❖ Some informal caregivers expressed difficult time sharing/expressing the caregiver burden with others



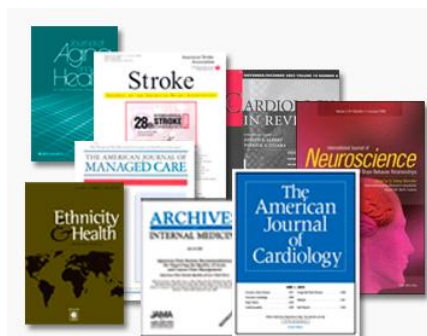
### ➤ Comparisons of Caregiver Groups

- ❖ Daily hands-on caregivers vs. intermittent hands-on caregivers
- ❖ Men vs. women informal caregivers
- ❖ End-of-life vs. long-term care vs. short-term care informal caregivers
- ❖ Rural vs. urban informal caregivers



### ➤ Communicating Caregiver Needs

- ❖ Open communication between informal caregivers and terminally ill loved ones was ↓
- ❖ ↑ length of caregiving for the terminally ill ↓
- ❖ ↑ open communication
- ❖ ↑ length of caregiving ↑ communication about end-of-life
- ❖ ↑ length of stay on palliative care units, ↑ desire to want more communication
- ❖ Due to avoidance, some informal caregivers did not want more information regarding the prognosis



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➤ Various Emotional Responses to Caregiving

- ❖ Ugandan informal caregivers considered hiring help
- ❖ Informal caregivers indicated that more training would be beneficial
- ❖ High level of strain among younger informal caregivers
- ❖ Physical, psychological and social strain was less with informal caregivers of cancer patients




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➤ Various Emotional Responses to Caregiving cont'd

- ❖ High subjective stress
- ❖ Quality of life of the informal caregiver decrease significantly over time
- ❖ Anxiety related to the fear of the unknown
- ❖ Role disturbance in women
- ❖ Feelings of inattention and neglect
- ❖ Informal caregivers felt trapped
- ❖ Exhaustion, tiredness, insomnia, lack of focus mental confusion



➤ Various Emotional Responses to Caregiving cont'd

- ❖ Informal caregivers with poor health and those who were younger in age had high prediction of stress
- ❖ Increase caregiver stress when terminally ill loved ones independence decreased
- ❖ Caregiver depression, anxiety and cognitive distress
- ❖ Psychological distress among younger caregivers



## Level VII Studies

➤ Caregiver burden

- ❖ Health effects
- ❖ Financial burden
- ❖ Inadequate preparation
- ❖ Illness
- ❖ Feelings of inadequacies





## Implications

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- Characteristics of the informal caregiver focus
  - Sociodemographics
    - Age
    - Relationship status
    - Financial status
    - Educational status
- Characteristics of the informal caregiver were assessed in conjunction with the terminally ill loved one



- 
- One was unable to discern the characteristics of the informal caregiver without evaluating their relationship to the terminally ill loved one/patient



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- Nursing community shouldn't ignore the characteristics of the informal caregiver
  - Understanding the informal caregiver is beneficial to a holistic approach to care for the terminally ill patient/loved one



- 
- Embracing the informal caregiver is key
  - Get to know them personally & individually
  - Address holistic approaches to include the family and the patient



## Recommendations

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- Bridge the gap in literature
- Conduct informal caregiver assessment upon admission
- Questionnaire to address, psychosocial, spiritual, and health assessment
- Mixed-method research
- Change the focus from patient-focus to a holistic approach
- Train nursing community

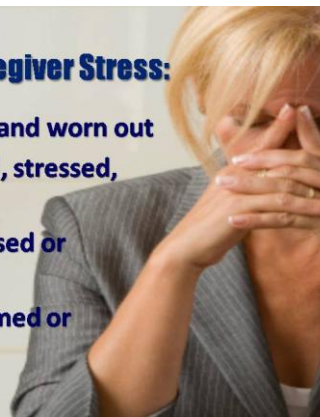


## Summary

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### **Warning Signs of Caregiver Stress:**

- **Physically – exhausted and worn out**
- **Emotionally – resentful, stressed, bitter**
- **Relationally – feeling used or unappreciated**
- **Financially – overwhelmed or depleted**



Google Image

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