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Methods of Engaging Family Systems at End-of-life

By

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MSW Clinical Research Paper

Presented to the Faculty of the
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St. Catherine University and the University of St. Thomas
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Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

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Abstract

Families are recognized in palliative and hospice care as being an integral part of end-of-life care, where they often provide informal caregiving to their terminally ill family members. Caregiving has been shown to put multiple burdens on family members and to negatively affect caregiver health, finances, and socio-emotional wellbeing. The need for end-of-life services in the United States is expected to drastically increase in the next few decades and the demands on families, friends, communities, and services around end-of-life needs will continue to increase as more people require end-of-life care. Therefore, this systematic review aimed to assess the research on nonmedical, psychosocial, family-oriented interventions used with family systems when an adult member (aged 45+) is at end of life and the effectiveness of these interventions. The family systems-illness model was used to guide this work. Eleven articles were found and assessed: Two reviews, four studies with psychoeducational interventions, and six studies with therapy-based interventions. The psychoeducational intervention studies were found to have better rigor, design, and sample sizes overall. The reviewed studies looked at various variables and found that overall the interventions had positive impacts on participants. There were findings of increased quality of life, coping, social support, hopefulness along with decreased depression, stress, reported physical symptoms of person at end of life, and negative views of caring. Attrition, standardization of measures, and inclusion of patients from other life limiting illnesses beyond cancer are all needed in further research. In addition, more studies need to be done that take into account the entire family system, and the stage and typical progression of different illnesses.

Keywords: end of life, palliative care, family, family system, psychosocial interventions, adults 45+

Systematic Review Project Proposal:

Methods of Engaging Family Systems at End-of-life

Death will affect each of us - in our lives through the loss of people we know and individually through our own inevitable death. In 2013, there were approximately 2.6 million deaths in the United States with the majority of deaths occurring over the age of sixty-five (Center for Disease Control and Prevention [CDC], 2015). This number is expected to steadily rise between now and 2050 (United States Census Bureau, 2014) as our population ages due to the large Baby Boom generation (Lynn & Adamson, 2003). To put this into perspective, The United States Census Bureau (2014) projects that the number of deaths will increase by 23 percent from 2015 to 2030 and 56 percent by 2050, while the population will only increase by 12 and 24 percent respectively. This means the death rate is expected to increase by 11 percent by 2030 and 33 percent by 2050 after population growth is considered. Therefore, individuals and families that need end-of-life services in the United States will drastically increase in the next few decades and the demands on families, friends, communities, and services around end-of-life needs will continue to increase as more and more people require end-of-life care.

When a person is terminally ill, family caregivers often carry a heavy physical, emotional, social, and financial burden (Blum & Sherman, 2010; Funk et al., 2010; Hudson & Payne, 2010; Stajduhar et al., 2010). The burden from caregiving can also have lasting negative health and psychological effects (Bernard & Guarnaccia, 2003; Stajduhar et al., 2010). The level of burden family caregivers experience is expected to increase since the pool of potential family caregivers (i.e. family members who provide physical, emotional, and social support to another member over time) for our aging population will be smaller than in the past due to reduced family sizes and changing family structures (Lynn & Adamson, 2003). Currently in the United

States, family members are often informal caregivers and advocates for other members at end-of-life (Funk et al., 2010; Stajduhar et al., 2010) and this trend is expected to increase. In the United States, approximately 34.2 million people were unpaid caregivers to someone over the age of 50 in the last 12 months, with 47 percent of these caregivers providing care for someone over the age of 75 (National Alliance for Caregiving and AARP Public Policy Institute, 2015). Of these, 85 percent provided care for a family member and 18 percent cared for more than one person. “On average, caregivers spend 24.4 hours a week providing care to their loved one” (NAC and AARP Public Policy Institute, 2015, p. 7). Also, the study found that 53 percent of caregivers said that at least one other unpaid caregiver helped provide care. One third (32 percent) of unpaid caregivers received help from a paid caregiver, such as a housekeeper, aid, or other paid professional. While another third, received no help from other paid or unpaid caregivers. These statistics show that people in the United States provide a large amount of support to older adults in their families.

Further, a comprehensive, two-part review of quantitative and qualitative research on home-based family caregiving at end-of-life that looked at 228 studies (105 qualitative and 123 quantitative) and found that extensive help was provided by caregivers to their ill relatives, while noting that the quality of the life of caregivers themselves was often negatively impacted (Funk et al., 2010; Stajduhar et al., 2010). Funk et al, (2010) identified multiple family caregiver psychosocial support needs, including informational support (i.e. information about providing basic care and about their relatives’ illness), emotional support, and social support. Additionally, Stajduhar et al. (2010) found that the multiple negative outcomes (e.g. psychological, financial, occupational, and patient care difficulties) family caregivers experienced outweighed the positive

ones (i.e. finding caregiving at end of life meaningful and rewarding) that were sometimes simultaneous reported.

To date, many palliative and end-of-life care practitioners, researchers and organizations have recognized the importance of engaging families in end-of-life care (Atilio & Otis-Green, 2011; Broom and Kirby, 2012; Brown & Walter, 2013; Canadian Hospice Palliative Care Association, 2013; Carolan, Smith, & Forbat, 2015; Emanuel & Librach, 2011; Grande et al., 2009; Gwyther et al., 2005; Hudson & Payne, 2011; Kristjanson & Aoun, 2004; Lynn & Adamson, 2003; McGuire, Grant, & Park, 2012; National Consensus Project for Quality Palliative Care, 2013; National Hospice and Palliative Care Organization, 2015a; Winzelberg, Hanson & Tulsky, 2005; World Health Organization, 2015). Yet, many note that family systems still have not been fully integrated into palliative and end-of-life care practices (Bernard & Guarnaccia, 2003; Broom and Kirby, 2012; Carolan, Smith & Forbat, 2015; Hudson & Payne, 2010; Vachon, Kristjanson, & Higginson, 1995; Wizeberg, Hanson, & Tulsky, 2005). Additionally, others have found that further research is still needed to identify effective family supports at end-of-life (Bern-Klug, Kramer, & Linder, 2005; Carolan, Smith & Forbat, 2015; Funk et al., 2010; Hudson & Payne, 2010; Stajduhar et al. 2010).

The National Consensus Project (2013) in their *Clinical Guidelines for Quality Palliative Care* (3rd Eds.) has patient and family centered care as one of its main tenants and in its recent update puts a “greater emphasis on interdisciplinary engagement and collaboration with patients and families to identify, support, and capitalize on patient and family strength” (p. 10). Broom and Kirby (2012) recommend that more nuanced attention should be focused on the challenges of diverse family situations in end-of-life care, while Bernard & Guarnaccia (2003) note that gender, age and relationship to care receiver may all affect caregiver burden and should be

further considered. In the end, most agree that family intervention is an important aspect of end-of-life care, but there are still many unknowns in this area of practice.

Psychosocial interventions are one way end-of-life professionals have tried to reduce some of the physical, emotional, and social burdens of end-of-life care for family members. Psychosocial interventions specifically are interventions that aim to meet the goals of the psychosocial framework, which are:

To restore, maintain, and enhance the personal and social functioning of individuals through mobilizing strengths, supporting coping capacities, building self-esteem, modifying dysfunctional patterns of thinking, feeling, and relating to others, linking people to necessary resources, and alleviating environmental stress. (Goldstein, 2008, p. 1)

These goals are broad, but the main aim is to improve psychosocial functioning and quality of life for individuals and family systems.

Social workers, because of their unique skill set, are ideally suited for meeting the mandate of supporting families in end-of-life care by providing nonmedical, psychosocial supports to families. These supports could encompass both psychoeducational and therapeutic components (such as time-sensitive counseling, dignity therapy, narrative therapy, life review, validation therapy, cognitive behavioral therapy, and motivational interviewing to name a few). It is also important that end-of-life professionals understand the range and efficacy of family interventions. Therefore, this systematic review aimed to take a critical look at the current research that has examined psychosocial interventions for terminally ill individuals, aged forty-five years or older, and their family members, and then determine the overall effectiveness of current interventions.

Family Systems-Illness Model

The main theoretical framework used as a lens to guide this work is the family systems-illness model developed by John Rolland. Rolland's (1994, 1999) Family Systems-Illness Model brings together systems theory and strengths perspective and provides a psychosocial structure in which to engage families experiencing a life-limiting illness over time. The model looks at three interconnected areas to gauge the best clinical intervention for the individual and family at the time: 1) The psychosocial aspects of the illness, 2) the life cycles of the terminally ill person, the family, and the illness, and 3) the encompassing belief systems that the family and its members have.

Psychosocial aspects of the illness. Rolland (1999) proposed a way of classifying diseases based on both biological and psychosocial components that took into account the type of onset (acute vs. gradual), the course of the illness (progressive, constant, or relapsing/episodic), the typical outcome, the level of incapacity caused by the disease (i.e. physical and cognitive effects), and the predictability of the illness. These factors combine to create a psychosocial map for the demands that a disease will make on the patient and family. Blum and Sherman (2010) notes that family caregivers of individuals with cancer often experience difficult transitions around the stages of the illness, and the ill members' often changing needs and symptoms. Therefore, an understanding of these transitions and an ability to recognize them in advance may allow families and health providers to anticipate problems and provide ways to minimize them.

Life cycle of illness. It is important to be aware that different illnesses have different courses, and each experience a "dynamic unfolding of the illness process over time" (Rolland, 1999, p. 246). There are three main life cycles that chronic, terminal illnesses follow especially in older adults (Lynn & Adamson, 2003), and these illness trajectories affect end-of-life care

(National Institute of Health, 2004). The first is indicative of mainly cancer, which plateaus at a relatively high level of functioning and leads to a short period of dramatic decline. The second characterizes a gradual, long-term decline with sporadic serious episodes, where functioning drastically decreases for a period of time; this illness trajectory is applicable to heart and lung failure. The third and final pattern is an extended, gradual decline and is indicative of illnesses such as dementia and disabling stroke. It should be noted that these are only general models that do not apply to everyone with a specific illness. Also, some illnesses have a high level of uncertainty (such as multiple sclerosis), which can hinder family planning, coping and adaptation.

In the Family Systems-Illness Model there are three main phases of a life-limiting illness that create different psychosocial challenges for the patient and family: Crisis, chronic and terminal. The crisis phase includes the initial emergence of symptoms, the diagnosis, and the initial period of adjustment and treatment planning. The chronic phase is usually indicative of one of the three trajectories described above with a plateau, episodic changes, or a steady downward progression in functioning (Rolland, 1999). The terminal phase encompasses the period when the family knows death is most likely imminent because of the illness, the family member's death, and the bereavement time afterwards (Rolland, 1999).

Individual and family life cycle. Additionally, the life cycle of the person with the life-limiting illness and the family can make a significant difference in what therapeutic interventions are necessary. For example, there can be large differences in needs if the person with a life-limiting illness is a child, a young adult, a middle-aged person with young children, or an elder. Each of these situations will need slightly different interventions based on where the individual and the family are in the life cycle. Also, the developmental level of other family members may

affect care. For example, if the person with a life-limiting illness is a married woman in her thirties with two young children at home, then the clinician would need to match interventions to the needs of the woman, her children (tailored to be age appropriate), her husband, their family and potentially other relatives such as siblings and parents.

Key family variables. The Family Systems–Illness Model (Rolland, 1999) looks at key family variables around beliefs and legacies that relate to health issues (such as beliefs about causes and what can affect an illness), medical care (i.e. do they exhibit trust or distrust of medical professionals), and how they face adversity (i.e. with optimism or pessimism, with a desire to learn or a closed-off approach, with reaching out to friends and family or shutting themselves in). These factors can either create a skewed focus of blame for cause of illness, or a high level of resilience and ability to problem solve in the face of a difficult situation. These family variables can greatly affect care, openness to care, choices of care, and health outcomes (Rolland, 1999).

Literature Review

Death in the United States

Since 2000, as hospice use has increased, so has the number of deaths that occur at home. Teno et al. (2013) found that the percentage of Medicare members enrolled in hospice care at the time of death increased from 21.6 percent in 2000 to 42.2 percent in 2009. At the same time, deaths at home increased from 30.7 percent in 2000 to 33.5 percent in 2009, while deaths in hospitals had declined from 32.6 percent in 2000 to 24.6 percent in 2009 and deaths in nursing homes stayed almost the same (Teno et al., 2013). The National Hospice and Palliative Care Organization (NHPCO, 2015) also looked at all hospice deaths and they found that 66.6 percent of hospice patients died in their place of residence in 2013 (41.7 percent in private residences,

17.9 percent in nursing homes, and 7.0 percent in residential facilities). As hospice use has increased, so has the rate of people dying at home – though to a slower degree.

These changes over time reflect the preferences of older adults and their families for end-of-life care. Older adults in the United States value their independence and therefore want to participate in the process of making decisions about their care and their end-of-life (Luptak; 2006; Piercy, 1998). Seventy-five percent of those at end-of-life wanted to stay in their own homes with 26 percent specifically stating they did not want to go to a nursing facility (Luptak, 2006). Gardner and Kramer (2009) also found that almost all of the terminally ill elders and their primary caregivers they interviewed associated dying at home with having a “good death.” It should be noted that even with the highest estimates of deaths at home, there is still a disconnect between elders wishes for place of death and the reality, since 75 percent want to stay at home (Luptak, 2006) and only 41.7 percent died in a private residence in 2013 (National Hospice and Palliative Care Organization, 2015). Since many dying individuals and their families want them to be able to die at home, the need for family, community and professional support will continue to increase.

Defining End-of-life

With current lifesaving medical interventions, the end-of-life can be ambiguous and is often difficult to pinpoint when it begins for most people (Bern-Klug, 2004; Lynn & Adamson, 2003; Izumi, Nagae, Sakurai, & Imamura, 2012; National Institute of Health, 2004). Many people pass away without a clear awareness that they are, in fact, dying. Add to this the fact that there are many terms and colloquialisms used to define dying and end-of-life care and each of these terms have different meanings for individuals, families, and even practitioners (Bern-Klug, 2004; National Institute of Health, 2004). For example, a life-limiting illness refers to a chronic

illnesses or condition where death is expected to be a direct consequence, such as cancer, heart disease, and dementia (Queensland University of Technology, 2014). Yet, many people today pass away after a protracted period of advanced chronic illness where the expected time of death is uncertain (Bern-Klug, 2004; Izumi et al., 2012; National Institute of Health, 2004). The National Institute of Health (NIH) states:

There is no exact definition of end of life; however, the evidence supports the following components: (1) The presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death. Older age and frailty may be surrogates for life-threatening illness and comorbidity; however, there is insufficient evidence for understanding these variables as components of end of life. (2004, p. 5)

Unfortunately, healthcare often does not recognize someone as dying until there are no longer any medical interventions that can be performed “to reverse the condition and preserve life” (Bern-Klug, 2004, p. 57). With this in mind, the regulatory environment and physicians have become the “gatekeepers” of when individuals transition from being sick to dying, yet their ability to predict how long individuals have to live is still difficult and often inaccurate (Bern-Klug, 2004; NIH, 2004). For example, the leading cause of death in the United States is heart disease (CDC, 2016), yet Lynn et al. found that physicians inaccurately predicted how long individuals had left by at least 6 months in a majority of cases (cited in Bern-Klug, 2004).

To combat this phenomenon, the World Health Organization (WHO, 2011) and the National Institute of Health (2004) recommend that palliative care along with curative treatments be offered from the time of initial diagnosis and be provided throughout the progression of the

disease until the end-of-life. This means we need to re-conceptualize our understanding of end-of-life to include people with chronic health conditions who are at a high risk for dying at uncertain times; this will help individuals and their families better cope with the uncertainty of their medical circumstances and provided needed supports (Bern-Klug, 2004; Gardner & Kramer, 2009; Lynn & Adamson, 2003; WHO, 2011).

Palliative and Hospice Care. Palliative and hospice care both focus on providing comfort and work to improve the quality of life through holistic interventions with individuals with a life limiting illness and their families. (Figure 1 below shows the role of hospice and palliative care at the end-of-life, their relationship with curative therapies and stage of the illness, and then bereavement support afterwards.) Palliative care and hospice care have a great deal of overlap, yet there are some differences. WHO (2015) defines palliative care as:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (p. 4)

Palliative care partners individuals suffering from serious and chronic illness and their families with a coordinated team of health professionals (Center to Advance Palliative Care, 2015), which are often based out of hospitals (Take Charge Partnership and Take Charge Online, 2004-2015). Palliative care can be used along with curative medical interventions by anyone of any age and at any stage during a serious illness (Center to Advance Palliative Care, 2015). Palliative care programs have significantly grown in the United States with 90 percent of large hospitals (300 or more beds) currently offering palliative care (Center to Advance Palliative Care, 2016).

Hospice care in the United States, on the other hand, focuses on a holistic approach to provide comfort care and support at the end-of-life without the further use of curative medical interventions. Hospice incorporates physical, emotional, social, and spiritual support for dying individuals and their families (Baker, 2005). Per the National Hospice and Palliative Care Organization (NHPCO, 2014), hospice is “considered the model for quality compassionate care for people facing a life-limiting illness” and their loved ones (p. 3). Hospice provides “medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes” (NHPCO, 2014, p. 3). In hospice, care is provided to the terminally ill individual usually in the home and a family member serves as the primary caregiver (hospice care is also provided in other places as well, depending on where the dying individual is located). Members of the hospice team regularly visit to assess how the patient is doing, and to provide any additional care or services that are needed (NHPCO, 2014). In the United States, in order for Medicare to pay for hospice, the dying individual’s care must shift completely from curative measures to palliative or comfort care, and a doctor needs to state that end-of-life is expected within six months.

Importance of Family at End-of-life

The term “family” continues to change over time and has sociological, cultural, legal and even individual definitions (Blum & Sherman, 2010). It can range from a narrow, traditionally Western view of the nuclear family (mother, father and their children) to encompass a broader definition made by the individual (Blum & Sherman, 2010; Kissane & Bloch, 2002; Reese, 2013). Blum states, “a simple definition of a family is two or more people who have come together for a self-defined common purpose” (as cited in Blum & Sherman, 2010, p. 244). This broader description of family refers to the people who are closest to the terminally ill person in

“knowledge, care, and affection” (Canadian Hospice Palliative Care Association, 2013, p. 92, & 2013, p. 4). Family, therefore, can include biological relatives, family acquired through marriage, and family of choice such as friends and even pets (Canadian Hospice Palliative Care Association, 2002; Reese, 2013).

It should be noted that when a terminally ill person is unable to voice who their family encompasses due to being incapacitated, legal parameters are usually followed even if this may go against the patient’s wishes (such as when LGBTQ partners have been sometimes excluded from end-of-life care by traditional family members who previously had been estranged). One way dying individuals can ensure their end-of-life wishes are more closely followed if they are incapacitated is to identify a trusted person to make decisions for them through the use of advanced healthcare directives (National Hospice and Palliative Care Organization, 2016). If no one has been designated, members of the person’s traditionally defined family (spouse, children, parents, siblings, grandchildren, etc.) and medical staff often become the ones making the healthcare decisions.

As stated earlier, most palliative care organizations and researchers identify family as a vital component of end-of-life care for most terminally ill individuals. Though most studies about those at the end of life only focus on family dyads (i.e. the terminally ill person and one family member such as the spouse, a primary caregiver or a child) (Heru, 2013), we still know some information about the importance of family at the end-of-life. The National Institute of Health (2004) stated that “family caregivers are central to end-of-life care because they provide emotional support,” “communicate with health care professionals,” and deliver “essential help with activities of daily living, medications, and eating” (p. 13). Downey, Engelberg, Curtis, Lafferty, and Patrick (2009) found that individuals at end-of-life and their families both rated

spending time with friends and family as one of two top priorities in having a quality end-of-life experience (second only to pain management).

Caregiving and being a family caregiver at end of life. Family members who provide “physical, emotional and instrumental support and assistance” to someone who they view as a member of their family are caregivers (Stajduhar et al., 2010, p. 587). This work is often voluntary and unpaid. Caregiving goes beyond the help family members often provide to each other normally and is often brought about because a family member needs assistance due to illness (Stajduhar et al., 2010).

Family members frequently provide some level of care for individuals at end of life. Schroepfer and Noh (2010) found that over three-fourths of interviewed home hospice patients were currently receiving support from family, friends, and even professionals (such as pastors) and anticipated continued support. Almost three-fourths of those receiving support even named specific people they knew they could count on. Piercy (1998) found that older persons often have multiple family members involved in their care. Blanton (2013) found that in many families grandchildren often provided emotional support to their grandparents and parents, as well as sometimes assisting with activities of daily living (ADLs), which are self-care tasks such as bathing, grooming, dressing, using the toilet, and eating. Even when dying family members live in nursing facilities, other family members are often still closely involved in their care because of the need for them to make often-difficult, end-of-life decisions (Waldrop & Kusmaul, 2011).

Additionally, the level of caregiving specific family members provides changes over time. Szinovacz and Davey (2007) found that within two years the make-up of adult-children caregivers of parents changed in 54.3 percent of families studied with the primary caregiver changing in over one fourth of cases. Moreover, race and ethnicity played a significant factor,

since African American and Hispanic families saw higher rates of caregiver change. These findings show that caring for family members is often a shared and changing process within families. Therefore, often multiple family members play important roles in the end-of-life care of an older member.

Effects of End-of-Life on Families

Families are often affected in profound ways when a member is diagnosed with a life-limiting illness. Life-limiting illnesses disturb a family's equilibrium and often create multiple losses within a family, such as the loss of roles, relationships, hopes, dreams, financial security, and the ill member (through physical and mental declines, and death) (Hooyman & Kramer, 2006; Walsh, 2006). Kiassane and Bloch (2002) found that half of patients, a third of their partners, and a fourth of their adult offspring experienced significant distress during end-of-life care, and this distress endured over time. Forbat, McManus, and Haraldsdottir (2012) found that a life limiting illness impacts the whole family system and often causes strain on family relationships. Additionally, Kissane, et al. (2003) found that families with poorly functioning relationships had higher levels of psychosocial distress.

As our population continues to age, integrating intergenerational family members into the end-of-life process of loved ones will become increasingly important in the next few decades. With the aging population in the United States familial pressures for end-of-life care will most likely increase and be spread across multiple generations within the family. This is especially true if the current trend of elders relying on their families to provide extensive support at the end of life continues. Due to these factors it is imperative that we look at how end of life affects the family system and vice versa.

Interventions

As stated, within the hospice and palliative care field families have been recognized as being an important area of intervention due to their important role in caring for their dying members. The National Hospice and Palliative Care Organization (2015b) outlines “patient and family-centered care” in its Standards of Practice for Hospice Programs ten key components. In addition, The National Consensus Project for Quality Palliative Care (NCP, 2013), which was supported by a wide consortium of hospice, palliative care, and social work organizations, extensively outlines incorporating the family throughout all aspects of care. Specifically, the “Social Aspects of Care” domain emphasizes “interdisciplinary engagement and collaboration with patients and families to identify, support, and capitalize on patient and family strengths” (NCP, 2013, p. 10).

A number of studies have been done that look at interventions that support caregivers. In a meta-analysis of diverse family oriented psychosocial interventions of patients with chronic illness, Hartmann, Bänzner, Wild, Eisler, and Herzog (2010) found that psychosocial interventions improved the physical and mental health of patients and their families compared to control groups. In fact, the findings showed that across the board, psychosocial interventions were more effective than commonly used treatments. Moreover, the longer the intervention, the more effective it tended to be. Additionally, family involvement was found to be a factor in sustained improvement over time. Although, this study looked at a wide array of chronic illnesses and often at interventions with only one family member, the results most likely have similar implications for end-of-life family interventions, since some of the examined studies included this population.

Family psychosocial interventions at end-of-life can have multiple positive impacts on the dying member and their family. The American National Working Group on Family-Based

Interventions in Chronic Disease categorize family-oriented interventions into two broad groups: Psychoeducational interventions, and family relationship interventions (Fisher & Weihs, 2000). The psychoeducational interventions focused on information about the disease and its impact on their lives, where the family relationship interventions instead focused on family functioning in the face of the disease. Hartman et al. (2010) found that overall family interventions improved both patient outcomes (mortality rates, better health, and less depression) and family member outcomes (physical health, and reduced caregiver burden). One caveat that Kissane and Bloch (2002) note is that psychosocial interventions during palliative care will not and should not be expected to drastically alter the functioning of families with long-standing issues, and that interventions should be aimed more at containing the families issues and developing modest goals. Unfortunately, family members often express feelings of not receiving appropriate, helpful or enough support from professionals (Dellmann-Jenkins, Blankmeyer, & Pinkard, 2000; Luptak, 2006).

A number of studies looked specifically at informal, family, or primary caregivers at end of life. Harding and Higginson (2003) did a systematic review of interventions for informal cancer and palliative caregivers of researched published between 1966 and 2001. They found 22 studies and examined a wide range of interventions (such as home care, respite care, social networks and activities, individual support, and group interventions). Overall, the study found the interventions to be helpful, but the rigor of the studies was low with the majority being descriptive or quasiexperimental studies. Hudson, Remedios, and Thomas (2010) reviewed studies that looked at psychosocial interventions for family caregivers of people receiving palliative care from 2000 to 2009. Fourteen studies were found that included a mixture of interventions that focused on a wide variety of areas (psychoeducation, psychosocial support,

caregiver coping, symptom management, sleep promotion and family meetings). Hudson et al. (2010) noted a slight increase in the quality of the studies, and the majority of studies reported the interventions had positive results. Candy, Jones, Drake, Leurent, and King (2011) did a meta-analysis of 11 studies of interventions that supported informal caregivers (dates searched were from 1872 to May 2010). They reported that the interventions did protect caregivers against psychological distress in the short-term, although the quality of the evidence was low due to small effect size and lack of study rigor.

This systematic review looked at what research since 2005 has been done on nonmedical, psychosocial interventions with multiple family members when an adult member older than 45 years is experiencing a life limiting illness, and whether the interventions have been found to be effective. Rolland's family systems-illness model is used to guide this work.

Methods

A systematic review was chosen in order to get a comprehensive picture of the recent research that has been performed on this topic. "A systematic review aims to comprehensively locate and synthesize research that bears on a particular question, using organized, transparent, and replicable procedures at each step of the process" (Littell, Corcoran & Pillai, 2008, p. 1). Therefore, a systematic review has specific predefined selection criteria for articles, a comprehensive search strategy, and an objective method for synthesizing and assessing the study findings. Petticrew and Roberts (2006) state that systematic reviews are appropriate when an accurate look of prior research and their methodologies is needed to promote new research in a specific area. At this time there is still a paucity of research that focuses on nonmedical, psychosocial interventions with multiple family members when a person is at end of life, yet many organizations have stated the importance of providing psychosocial support to these

families. Therefore, this systematic review looks at the current research in order to see if any effective interventions with families who have an older member at end of life have been found and then to recommend where further research is needed.

Inclusion Criteria

To meet the objective of this systematic review three main categories of variables were selected to direct the article searches around the concepts of end-of-life, the family, and nonmedical, psychosocial interventions performed. Additionally, since the objective of this review was to identify effective psychosocial family interventions, which can assist professionals working with older adults at end of life in the United States, some specific inclusion and exclusion criteria were used. Specifically, only peer-reviewed research articles written in English from the United States, Canada, United Kingdom, and Australia were included. Although, the healthcare systems, policies, and end-of-life care in these countries do vary, the similarities were believed to be similar enough to include them in order to get a more robust view of the work being done in this area.

There were a number of criteria that were used to determine if the studies included were psychosocial in nature. Broadly, the intervention needed to attempt to “restore, maintain, and enhance the personal and social functioning of the individuals” (Goldstein, 2008, p. 1). This could be through education and/or therapy. Additionally, the study needed to evaluate how these interventions affected how a person was doing in the personal and/or social realms. Due to the desire to look at broader effects, studies that only focused on the physical affects of interventions (such as effects on pain management) were excluded. The studies needed to look at a broader pool of quality of life markers such as levels of stress, depression, social support, spirituality, hope, etc.

Since this review is focused on older adults at end-of life and their families, research focusing on children and young adults at end-of-life and their families was excluded. To achieve this, only studies with an average age of 45 or older for the person at end of life were included. Additionally, since we are looking at family interventions, studies that looked at data from only one family member were also excluded. Ideal articles would have included multiple family members within the same family. This could be the person at end of life and their primary caregiver, though the hope was to find studies that looked at the effect of interventions on multiple family caregivers.

Additionally, due to the limited amount of studies that included more than one family member (either in the intervention, as respondents in the study, or both), a wide range of studies was included in the review. Therefore, the majority of the studies examining the effects of psychosocial interventions were included if they had more than one member in any of those three areas. The types studies reviewed for consideration included reviews, feasibility studies, evaluation studies, descriptive studies, and evaluation phase II and III studies. Theory or framework development papers, policy documents, study protocols, case studies, and expert opinions were excluded from consideration.

Search Strategy

Several strategies were used to create the initial pool of potential studies. Eight electronic databases were searched for potential research articles: Academic Search Premier, CINAHL Plus, Family Studies Abstract, Health Source: Nursing/Academic Editions, MEDLINE (EBSCO), PsychINFO, Social Work Abstracts, and SocINDEX. Since end-of-life care has been a rapidly evolving field that only recently has begun to emphasize psychosocial interventions

directed at families and since a number of studies have looked at primary family caregivers, only articles published between January 1, 2005 and January 30, 2016 were examined.

A number of search terms were used in order to comprehensively look at the question this study poses. These terms were chosen to endeavor to encompass the three main areas of: 1) End of life, 2) family, and 3) non-medical, psychosocial interventions (see Table 1). For end of life the terms “hospice,” “end of life care,” “palliative care,” or “terminal* care” were used, since as explained a lot of variation exists in current terms in use. For the family, the terms employed were “family caregiver*,” “informal caregiver*,” “relative*,” “family system*,” “famil*,” or “lay care*.” Finally, for interventions, the terms “intervention,” “treatment,” “support,” or “therap*” were used. There were also limiting terms, which were excluded. These were “medical,” “medication,” and “children.”

The titles and abstracts were then looked at to determine which full articles to look at further. From these full articles additional articles were extracted from the references to be examined. Then from this group, the final articles were chosen based off the selection criteria.

Data Extraction and Analysis

Data was extracted from each article to synthesize the results through the use of an article analysis form (see Appendix A), which looked at authors, publication date, location, study aims, variables, study design, data collection, sample demographics, intervention, analysis methods, results, ethical considerations, and conclusions. The following items were reviewed: 1) The question or hypothesis the research examined (with the independent, dependent, and control or intervening variables defined), 2) the sample information (such as the family members included, illness and age of family member at end of life, sample size, and other characteristics, such as age, country and ethnic composition), 3) aspects of the research design (including type of study,

when the intervention was performed, when were measurements taken, and how was the data gathered), 4) information on the data collection and analysis, 5) the research findings and conclusions (including impressions of validity), and 6) any ethical issues discussed.

For ease of discussion, the articles were then divided into three categories:

Psychoeducational interventions, therapy interventions, and reviews. The reviews were separated, since they both contained psychoeducational and therapy interventions. The two intervention types (psychoeducational and therapy) were also separated to see if there was any difference in the finding between the two categories, and then to see if these matched the findings from the included reviews.

Each article was then rated in nine categories (abstract and title, introduction and aim, method and data, sampling, data analysis, ethics and bias, findings/results, transferability/generalizability, and implications and usefulness) from 1 (very poor) to 5 (excellent) based on the clarity and rigor of each area. A score of 1 was designated for poorly developed areas. This means studies with multiple flaws, such as studies without a clear hypothesis/question, where the characteristics of the sample were not clearly defined, lack of a rigorous study design, findings were not clearly explained or supported, measures were not previously validated, or ethical considerations were not discussed. On the other hand, studies with high clarity and study rigor that also have a high chance of applicability to the broader public (such as well designed, meta-analysis studies) would have received a 5 in each category.

The articles were then organized based on the type of intervention (psychoeducational or therapeutic), and these ratings. Systematic reviews were organized separately using these ratings for two reasons: First, they provide a good comparison for the bulk of the other studies, and, second, they also could examine multiple types of interventions so placing them in one category

could have been difficult. From this initial data extraction, the data was then synthesized across the research to highlight the strengths and limitations of the interventions and how these studies lined up with the Family System-Illness Model.

Results

Search Results

The search criteria yielded a total of 1,688 citations: 621 from Academic Search Premier, 615 from Health Source: Nursing/Academic Editions, 130 from Family Studies Abstract, 109 from SocINDEX, 100 from MEDLINE (EBSCO), 79 from CINAHL Plus, 27 from Social Work Abstracts, and 7 from PsychINFO (Figure 2). The titles and abstracts of these citations were further screened to narrow them down to relevant research studies. This yielded a total of 30 articles, of which the full text was then reviewed. From these articles, an additional 24 new texts were identified and also reviewed. From the 54 full text articles eleven met the research criteria: Two reviews (Chi, Demiris, Lewis, Walker & Langer, 2015; McClean & Jones, 2007), which contained studies on both psychoeducational and therapeutic interventions (see Table 2), four studies on psychoeducational interventions (Kilbourn et al., 2011; Meyers et al., 2011; Northouse, Kershaw, Mood, & Schafenacker, 2005; Northouse et al., 2007) (see Table 3), and five studies on therapy interventions (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008; Hall, Goddard, Speck, Martin, & Higginson, 2013; McClean et al., 2008; Roth, Mittelman, Clay, Madan, & Haley, 2005; McClement et al., 2007) (see Table 4).

There was some overlap of the articles included in the reviews and the ones included in the other two groupings. The psychoeducational intervention study by Meyers et al. (2011) was included in the review by Chi et al. (2015), and the psychoeducational intervention study by

Northouse et al. (2005) was included in the review by McLean and Jones (2007). All of the other articles in the reviews (13 in Chi et al. [2015] and 5 in McLean & Jones [2007]) were different.

Characteristics of Included Studies

Published Journals. The eleven articles were published in six journals by nine different first name authors and took place in four different countries. Two of the six journals covered end of life issues: *Journal of Palliative Medicine* (Allen et al., 2008; Kilbourn et al., 2011; McClement et al, 2007; Meyers et al., 2011), and *American Journal of Hospice and Palliative Medicine* (Chi et al, 2015). Two were about symptom management: *Psycho-Oncology* (McLean & Jones, 2007; McLean et al., 2008; Northouse et al., 2005) and *Journal of Pain and Symptom Management* (Hall et al., 2013). One was about cancer care: *Cancer* (Northouse et al., 2007). Another one was about aging: *Psychology and Aging* (Roth et al, 2005). In the systematic reviews, Chi et al. (2015) and McLean and Jones (2007) had very similar results. There were two first named authors who had two studies each in this review; Linda McLean had a systematic review (McLean & Jones, 2007) and a therapy study (McLean et al., 2008), while Laurel Northouse had two psychoeducational studies (Northouse et al., 2005; Northouse et al., 2007).

Where the Studies Occured. Overall there were seven studies from the United States (Allen et al., 2008; Chi et al., 2015; Kilbourne et al, 2011; Meyers et al., 2011; Northouse et al., 2005; Northouse et al., 2007; Roth et al., 2005), three from Canada (McClement et al., 2007; McLean, & Jones, 2007; McLean et al., 2008), one from Australia (McClement et al., 2007), and one from the United Kingdom (Hall et al., 2013). McClement et al. (2007) was the only article that had participants in two countries: Australia and Canada. Chi et al. (2015) had similar results with studies conducted in the United States (six studies), Australia (five studies), Canada (one

study), Germany (one study), and United Kingdom (one study). McLean and Jones (2007) did not mention the countries of the studies.

Settings of the Interventions. The settings in which the studies occurred were predominately medical facilities, such as hospitals or clinics (Meyers et al., 2011; Northouse et al., 2007; Roth et al., 2005; Hall et al., 2013; McLean et al., 2008) or at the subjects' homes (Northouse et al., 2005; Kilbourn, et al., 2011; Allen et al., 2008). McClement et al. (2007) stated that the interventions were done at sites in Canada and Australia, but they did not define what type they were. In the systematic reviews, Chi et al. (2015) found the settings were at home (eight studies), hospitals (four studies), and nursing home or community (four studies, two in community hospices). McLean and Jones (2007) found three of the five study sites were at home with two not specifying the site.

Study Designs. Overall, there were two reviews (Chi et al. 2015; McClean & Jones, 2007), five randomized-control trials (RCT) (Allen et al., 2008; Meyers et al., 2011; Northouse et al., 2005; Northouse et al., 2007; Roth et al., 2005), one one-group, intervention only feasibility study (Kilbourn et al., 2011), one quasiexperimental, pilot study (McLean et al., 2008), and two qualitative studies (McClement et al., 2007; Hall et al., 2013). The studies that had the psychoeducational interventions had the highest number of RCT studies (three of four) (Meyers et al., 2011; Northouse et al., 2005; Northouse et al., 2007) compared to two of five in the therapy studies (Allen et al., 2008; Roth et al., 2005). Chi et al. (2015) found two three-armed RCT studies, five RCT studies, one randomized comparative, noninferiority study, one comparative study, and five quasiexperimental studies. McLean and Jones (2007) found two RCT studies, two quasiexperimental studies, and one case study.

The majority (six) of the studies had multiple data collection points over time after assessing participants' baseline (Kilbourn et al., 2011; McClement et al., 2007; McLean et al., 2008; Meyers et al., 2011; Northouse et al., 2005; Northouse et al., 2007). All except the two qualitative studies had at least a baseline measurement with a post-intervention assessment. The qualitative studies took baseline demographic information and then the qualitative interviews after the interventions. Chi et al. (2015) found similar results with 10 of 14 studies having multiple post baseline assessments, and all having at least a baseline and post-intervention assessment. McLean and Jones (2007) found one longitudinal study, three pre- and post-test studies, and one case study.

Sample Sizes and Characteristics. There was a wide range of sample sizes found. For the psychoeducational and therapy intervention groups, the sample sizes ranged from 16 couples (McClean, 2008) to 476 patient/caregiver dyads (Meyer et al., 2011). The sample sizes of the four psychoeducational studies were: 29 caregivers (Kilbourn et al., 2011), 134 dyads (Northouse et al., 2005), 234 dyads (Northouse et al., 2007), and 476 dyads (Meyer et al., 2011). The therapy studies had sample sizes that ranged from 16 couples to 312 spouses: 16 couples (McClean et al., 2008), 29 patients and 9 family members (Hall et al., 2007), 31 dyads (Allen et al., 2008), 60 family members (McClement et al., 2007), and 312 spouses (Roth et al., 2005). The two systematic reviews had studies with sample sized ranging from 476 dyads to one couple (a case study). Chi et al. (2015) had larger sample sizes with five articles having more than 200 participants (range of 10 to 476 dyads); McLean and Jones (2007), which looked at couple interventions, had only one study with the number of participant dyads over 100 with the majority (three studies) under 15 participant dyads.

The demographics for the majority of the studies are relatively homogenous. The majority of the terminally ill family members had cancer. In six of the studies all of individuals at end of life had cancer (Hall et al., 2013; McLean & Jones, 2007; McClean et al., 2008; McClement et al., 2007; Meyers et al., 2011; Northouse et al., 2005; Northouse et al., 2007). Three studies had mixed terminal illnesses with the largest percentages in each having cancer. In Chi et al., (2015), 8 of the 14 studies were about caregivers of cancer patients, while another study had 86% with cancer; one study was of family caregivers of people with dementia, and the four remaining studies were of undefined palliative care and hospice patients. In Kilbourn et al. (2011), 48% had cancer and 35% had a neurological condition such as dementia. In Allen et al. (2008), 52% had “general debility/multiple chronic illnesses” and 23% had heart disease. Roth et al. (2005) looked at spouses of individuals with Alzheimer’s disease.

The mean age of the patients in the psychoeducation and therapy studies ranged from 54 years (McClean et al., 2008) to 75 years (Allen et al., 2008) with all but two studies (McClean et al., 2008; McClement et al., 2007) having a mean age of 60 or above. The mean ages of the terminally ill family member were higher in the therapy studies. Three had mean ages of 65 or above (Roth et al., 2005; Allen et al., 2008; Hall et al., 2013) versus none in the psychoeducational studies. McClean et al., 2008, looked at the couple as a whole, so the mean age (48 years) includes both the ill person and their spouse. Neither of the reviews included the mean age of the patients in their studies.

Overall, the mean ages of the family members/caregivers were lower than for the terminally ill family members. The range was from 52 years (Northouse et al., 2005) to 71 years (Roth et al., 2005). The mean age of the caregivers was lower than the ill family member in all of the studies that included the ages of both groups. Chi et al., (2015) reported the mean age of

caregivers was between 55 and 73 years old with the majority in the high 50s and low 60s (the patient ages were not included). McLean and Jones (2007) did not cite the mean ages of the study participants in their review.

The family caregivers in the studies were mostly women. In five of the studies (Allen et al., 2008; Chi et al., 2015; Killbourn et al., 2011; McClement et al., 2007; Northouse et al., 2007; Roth et al., 2005) women were the majority of the caregivers/family members included. Two studies had a majority of male caregivers (Meyer et al., 2011; Northouse et al., 2005). Two studies about couples (McLean & Jones, 2007; McLean et al., 2008) did not separate the demographic information for the ill person and their partner, so it is unknown how many caregivers were female or male. Hall et al. (2013) did not include any demographic information about the family members. The gender of the terminally ill person was only included in three studies (Allen et al. 2008; Hall et al., 2013; Meyer et al., 2011) and was more evenly divided with 74 percent, 51 percent, and 55 percent who were female respectively. There were two psychoeducational studies about types of cancer that predominately affect one gender, i.e. prostate cancer (Northouse et al, 2007) and breast cancer (Northouse et al., 2005). The rest of the studies did not include the gender information of the terminally ill family members.

Types of Interventions and Conceptual Frameworks. There were three different psychoeducational based interventions, and four therapy based interventions in this review. The psychoeducational interventions were:

- COPE (Creativity, Optimism, Planning, and Expert information), a model which teaches individualized cognitive and behavioral problem-solving skills and was completed in three sessions (Meyers et al., 2011).

- FOCUS Program, a supportive and educational intervention, which had five content areas (family involvement, optimistic attitude, Coping effectiveness, uncertainty reduction, and symptom management) (Northouse et al., 2005; Northouse et al., 2007). The intervention was delivered in three 90-minute home visits and 2 30-minute phone sessions (2 weeks apart).
- The Caregiver Life Line (CaLL), a telephone based program “aimed to improve coping skills and integrating a sense of meaning into caregiving activities,” which was delivered in 10 to 12 semi-structured calls (Kilbourn et al., 2011, P. 1200-1201).

The therapy interventions were:

- An enhanced counseling and support intervention that had three components (two individual and four family counseling sessions, a support group, and ongoing, ad-hoc telephone counseling) (Roth et al., 2005).
- An interventionist guided legacy activity based off of life review and dignity therapy, where the terminally ill person and a family caregiver work on a meaningful project (such as a cookbook, scrapbook, audiotapes, etc.) that can be given to family members as a remembrance for when the ill person dies (Allen et al., 2008). The intervention took place in three sessions with average times of 82 minutes, 66 minutes, and 70 minutes for each.
- Emotionally focused couple therapy (EFT), “a short-term (8-20 sessions) manualized intervention designed for distressed couples” (McLean et al., 2008, p. 1153) which was modified by McLean et al. for cancer patients and their spouses. An average of 12 sessions were completed.

- Dignity therapy, where participants are interviewed about what is important to them and what thing they wish to share with their loved ones in order to create a “generativity” document to then share with their family and friends (McClement et al., 2007; Hall et al., 2013). Neither study discusses in detail the intervention.

Chi et al. (2015) included educational (four studies), psychoeducational (four studies), and cognitive behavioral (six studies) interventions. McLean and Jones (2007) included therapy (four studies), and a psychoeducational intervention (one study).

Overall there were four studies that included an clear discussions of the frameworks that guided their work: Northouse et al. (2005) had an in-depth section on the stress-appraisal model; Allen et al. (2008) included Folkman’s stress process model; and Hall et al., (2013) and McClement et al. (2007) discussed the tenets of the dignity model. Two additional studies only briefly mentioned theories without clearly defining or naming them: Attachment style (McLean & Jones, 2007), and stress and coping theories (Roth et al., 2005).

Variables and Measures. The studies looked at a wide range of different variables. The psychoeducational studies measured 14 different variables: Quality of life (Kilbourn et al., 2011, Meyers et al, 2011; Northouse et al., 2005; Northouse et al., 2007), problem-solving ability (Meyers et al, 2011), appraisal of illness (Northouse et al., 2005; Northouse et al., 2007), appraisal of caregiving (Northouse et al., 2005; Northouse et al., 2007), coping (Northouse et al., 2005; Northouse et al., 2007), symptoms (Northouse et al., 2007), risk for distress (Northouse et al., 2007), uncertainty (Northouse et al., 2005), hopelessness (Northouse et al., 2005), caregiver depression (Kilbourn et al., 2011), stress (Kilbourn et al., 2011), perceived social support (Kilbourn et al., 2011), benefit finding (Kilbourn et al., 2011), and the ability to use coping skills (Kilbourn et al., 2011). Every study measured quality of life with the only other duplicate

variables found in the two studies lead by Northouse (Northouse et al., 2005; Northouse et al., 2007).

The therapy studies measured 12 different variables: caregiver depression (Allen et al., 2008; McClean et al., 2008; Roth et al., 2005), patient depression (Allen et al., 2008, McClean et al., 2008), caregiver self-assessment of stress (Allen et al., 2008; Roth et al., 2005), social support (Roth et al., 2005), caregiver's perception of the ill person's symptoms (Allen et al., 2008), caregiver religiosity/spirituality (Allen et al., 2008), caregiver and patient hopelessness (McClean et al., 2008), patient's physical symptoms (Allen et al., 2008), patient's level of interactions (Allen et al., 2008), patient's wellbeing (Allen et al., 2008), patient's meaning based coping (Allen et al., 2008), and marital functioning (McClean et al., 2008). The most measured variables were caregiver depression (three studies), patient depression (two studies) and caregiver stress (two studies).

The measurement tools used were as diverse as the variables. Due to this fact only the measures used for the most included variables are examined here (for a full list see Tables 3 and 4). In the four psychoeducational studies, quality of life (QOL) was measured using three different instruments, using seven different versions total (City of Hope QOL, Medical Outcomes Study 12-item short form [patient and caregiver versions], Functional Assessment of Cancer Treatment [General, Prostate and Breast cancer versions], and Medical Outcomes Study 36-item short form health survey). In the therapy studies, caregiver and patient depression were measured with 3 different measures (Geriatric Depression Scale, Center for Epidemiological Studies – Depression Scale, and Beck Depression Inventory-II); while caregiver self-assessment of stress was measured with the Memory Behavioral Problem Checklist (MBPC) and Caregiver Stressors Scale. The two qualitative studies used questionnaires created by the researchers.

The two reviews, Chi et al. (2015) and McClean and Jones (2007), found similar results with a wide range of measures used to examine an equally wide range of variables.

Outcomes. Overall, there were positive outcomes for the interventions. The studies reported increased: Social support (Kilbourn et al., 2011; Roth et al., 2005), caregiver coping (Kilbourn et al., 2011; Northouse et al., 2007), hopefulness (Hall et al., 2013; Northouse et al., 2007), caregiver quality of life (Northouse et al., 2007), caregiver emotional/social quality of life (Kilbourn et al., 2011), patient's level of social interaction (Allen et al., 2008), patient's meaning based coping (Allen et al., 2008), marital functioning (McClean et al., 2008), patient's sense of dignity (McClement et al., 2007), and patient coping (Northouse et al., 2005).

Also reported in the studies were decreased: Caregiver depression (Allen et al., 2008; Kilbourn et al., 2011; McClean et al., 2008; Roth et al., 2005), caregiver stress (Allen et al., 2008; Kilbourn et al., 2011; Roth et al., 2005), patient reported symptoms (Allen et al., 2008; Northouse et al., 2007; Northouse et al., 2007), patient depression (Allen et al., 2008; McClean et al., 2008), negative views of caregiving (Northouse et al., 2005; Northouse et al., 2007), patient hopelessness (Northouse et al., 2005), uncertainty (Northouse et al., 2007), caregiver physical quality of life (Kilbourn et al., 2011), and quality of life at half the rate of the control group (Meyers et al., 2011).

There were some additional findings. Roth et al., (2005) looked for predictive factors and determined through structural equation modeling (SEM) that caregiver satisfaction and social support are inversely correlated with perceived stress in caregivers of people with Alzheimer's. Northouse et al. (2007) found that the positive effects of the intervention seen with the patient at four months were not maintained at eight and twelve months, but the improvements with the intervention group caregivers were. Northouse et al. (2005) found that none of the positive

effects found at three months were maintained over time at six months. Both qualitative studies found the dignity therapy intervention helpful for patient and family (Hall et al., 2013; McClement et al., 2007). The two reviews found similar results in their studies (Chi et al., 2015; MCLean et al., 2007).

Discussion

Study Countries

The studies included all came from Western, English-speaking countries. This is not surprising due to the selection criteria. Interestingly, four studies from Australia were excluded due to their focus being only on the primary caregiver. This suggests that research about the end of life psychosocial interventions in Australia may not have been focused on multiple family members or the family system.

Study Settings

It was not surprising to find that in three of the studies the interventions were done in the home, since as discussed earlier the majority of people at end of life prefer to remain at home. Five of the studies had the interventions performed in medical facilities. Besides the fact that people at end of life are receiving care from these facilities, the high percentage of studies at these sites may also be driven by the fact that these facilities have the staff and infrastructure to perform these types of studies more easily. It was surprising to find that long-term care facilities were only mentioned by Chi et al. (2015) as an intervention setting, since in 2013, 17.9% of deaths took place in nursing homes in the United States (NHPCO, 2014). This may be due to a number of factors: Nursing homes may have been counted as the terminally ill person's place of residence, possibly nursing homes are not as focused on researching family system interventions,

the people doing research in this area are not connected to nursing homes, or nursing homes do not have the infrastructure or staff to perform these studies.

Sample Characteristics

As for the study samples, there are a number of things to note. Overall, the majority of full text articles reviewed (21 total) were discarded because the focus of the study was on only one family member. It is true that two people (a person at the end of life and their primary caretaker) can make a family, but reducing most families to a specific dyad does not provide a clear picture of what most families look like or accurately shows the potential impact of the interventions. Also, as shown in the literature, most individuals often have multiple people involved in their care (Alliance for Caregiving and AARP Public Policy Institute, 2015), and the make-up of caregivers frequently changes over time, especially in African American and Hispanic families (Szinovacz & Davey, 2007 & 2013). There was only one study (Roth et al., 2005) that actively targeted multiple family members by requiring the participant to have at least one more family member in the area (in addition to the patient and spouse) and by having four family counseling sessions. This study, even though part of the intervention targeted multiple family members, only measured variables from the primary spouse.

Due to the homogenous nature of the sample in most of the studies, there are most likely issues of generalizability. In most of the studies cancer was either the only illness included or the main terminal illness. Moreover, Chi et al. (2015) found that cancer was the dominating illness in the studies, and McClean and Jones (2007) only looked at couples facing cancer. This has the potential of significantly limiting generalizability to the majority of hospice families, since the NHPCO (2014) reported that only 36.5% of hospice admissions were for cancer.

Another factor with potential generalizability issues lies with the gender of the caregivers. Since the majority of caregivers were female, these interventions may not have the same effect on male caregivers. McClean et al. (2008) did look at if there were differences between the responses of men and women in the study, but theirs was the only study that did.

Additionally, there were few non-English speakers or people of color included in the majority of the studies. All of the studies, except for McClean et al. (2008) had criteria for participants to be proficient in English. Therefore, the interventions may not be appropriate for non-English speaking families. Also, in all studies, except one (Allen et al., 2008), the large majority of participants were Caucasian with few people of color. Therefore, generalizability to other races or ethnicities is limited.

Research Designs and Interventions

As for research design and rigor, overall the psychoeducational studies were stronger with three of the studies being well-designed, randomized control trials (Meyers et al., 2011; Northouse et al., 2005; Northouse et al., 2007). All of the randomized control trials looked for variations between the samples of the intervention group and the control group, and statistically adjusted for any found differences (Allen et al., 2008; Meyers et al., 2011; Northouse et al., 2005; Northouse et al., 2007; Roth et al., 2005). Also, these studies standardized the intervention provided across the interventionists through training and use of standardized materials. Northouse et al. (2005 & 2007) also had the interventionists meet regularly to ensure consistency. For increased rigor, Northouse (2007) assigned separate assessors who were blinded to the participant's group assignment to ensure there was no bias in the data caused by the assessors.

Of the two qualitative studies, Hall et al. (2013) was the stronger study. In it, the methods and framework approach taken to analyze the descriptive data were described clearly.

McClement et al., 2005 did not include much information on the method and did not describe the analysis method used.

For the two reviews, Chi et al. (2015) was the stronger study. The study methods were clearly defined and the study findings were clearly presented with structural comparisons made across the included studies. McClean and Jones (2007) in comparison did not clearly define the methods used. Also, the information was presented by summarizing each article separately with little thematic or structural comparisons made across the studies.

Measures

The majority of the studies, which were random control trial and quasiexperimental designs, used quantitative measures for the psychosocial outcomes that have been tested for reliability and validity. The studies looked at a variety of factors and they used a number of different measures to examine similar outcomes. For example, in measuring quality of life there were four different instruments with seven variations used by the four psychoeducational studies (Kilbourn et al., 2011; Meyers et al., 2011; Norhouse et al., 2005; Northouse et al., 2007). Lack of standardization of measures makes it difficult to compare the results of the different studies beyond noting if they found positive results or not. This is especially true since the studies looked at different factors to determine quality of life for participants.

Roth et al. (2005) in their longitudinal, randomized control trial found that the original measures did not accurately measure the factors that impact the caregiver's perceived stress and depression. Therefore, they examined the available data to come up with a more accurate statistical model to determine which factors impacted caregiver stress and depression. In the end,

through the use of structural equation modeling the study determined that the caregiver's satisfaction with social supports was the main predictor of reduced stress and depression.

As shown the majority of the studies measured information at multiple times after the baseline. This is important since it can show the effectiveness of interventions over time. For example, Northhouse et al. (2007) found that the effects of the intervention for the patient did not last over time, while for the caregiver they did and in fact the effects became even more pronounced in some areas.

Outcomes

Overall, the studies reported positive outcome for a wide mixture of psychosocial variables. As stated earlier, comparability between studies would be much easier, if the measures had been standardized.

Limitations Found

The main limitations identified in the studies were: High attrition, the chance of a type I error (i.e. the finding may have occurred by chance), selection bias, limited ethnic diversity in the participants, limited diversity in the different stages of the illness, generalizability to individuals without a spouse, generalizability to individuals who do not have cancer, the English language requirement, small sample size, lack of a control group, and potential treatment diffusion (due to control group participants receiving therapy from outside sources).

In the studies with high attrition rates, death of the terminally ill person was often the main reasons. Northhouse et al. (2005) examined the baseline scores of those who left the study and compared them to those who completed it. They found that the people who left the study started out with more symptoms and more uncertainty about the disease than those who completed it. In fact, seventy-nine of the patients who left the study died during the study. Other

studies purposefully screened extremely ill people from entering the study (McClellan et al., 2008; Meyers, et al., 2011; Northouse et al., 2005). One issue they noted with this is that the effect of the interventions may not be as apparent since the participants baseline physical and mental health was higher, and therefore the effects that would be seen with individuals with more symptoms and their families may have been mitigated.

Additionally, as Roland (1994, 1999) notes it is important that multiple aspects of the person with a terminal illness be examined (the phase and the course of the illness, the psychosocial impacts of the illness, and the key variable of the family system). Although all of the studies were about people with a terminal illness, only Northouse (2005 & 2007) discussed the potential impact to the research of only having a very small percentage of the participants in a late stage of their illness. Stajduhar et al., (2010) also noted the importance of identifying the stage of illness in research about caregivers at end-of-life. Also, none of the researchers commented on the potential effects of the typical disease progressions of the illness included in the study.

There are challenges to this work. Families who have one of their members at end of life are a vulnerable population and adherence to strong ethical standards and safe practices for the participants needs to occur. Also, this population can be difficult to study due to high rates of attrition. In the end, the need for research to determine effective psychosocial interventions with family systems is enormous due to our aging population, and the need will only increase going forward.

Implications for Practice

Interventions used with individuals at end of life and their families need to more consistently look at the whole family system. As shown, the end of life of an individual has

profound impact on that person's family. Since, the generalizability of these findings to families facing other illnesses than cancer, to male caregivers, or to non-Caucasian or non-English speaking families may be limited, caution should be taken when using these interventions with these populations. Agencies and people who work with families at end of life should continue to explore family interventions at end of life with diverse populations and use standardized measurements to test the results. Additionally, since Roth et al. (2005) found that a caregiver's satisfaction with social support was a significant predictor of his or her perceived stress and depression; interventions that bolster the quality of social supports should be explored further.

Directions for Future Research

Location. In future studies, more attention should be taken in defining any differences between the residences of the terminally ill persons, or the location of the intervention. More nursing home residents should also be incorporated into sample populations. Additionally, it should be researched whether the intervention site affects participation and/or attrition rates, since the added burden of travelling to a clinic may make it more difficult for families with very ill members to participate.

Sample. There were three main issues with the studies samples that future studies should address. The majority of studies focused on: 1) individuals of dyads, 2) individuals with cancer, and 3) Caucasian, English-speaking participants. Since the current mandates from all of the large health and palliative care organizations state that supporting the family is a priority, the research needs to expand to meet this directive more fully. Only including primary family caregivers or patient/caregiver dyads excludes the majority of many families. Also, those families facing cancer dominated the studies. Since cancer only covers a percentage of illnesses families face, it is extremely important that future studies work to expand their sample to include people with

other life-limiting illnesses. Finally, future research needs to determine the effectiveness of intervention on non-English speakers and families of different races and ethnicities.

Another factor that may affect family caregiving, but was not examined, are whether or not the family caregivers have multiple caregiving roles. For example, the sandwich generation, which is comprised of middle-aged adults who provide care for their older parents and children. Examining these types of broader, psychosocial factors affecting the family may provide some better insights into what factors impact the quality of life of family members.

Design. Initial pilot studies are important and more should be done to see a wider range of family interventions. Additionally, more randomized control studies with larger sample sizes are important to gain better insight about generalizability. Finally, future studies need to continue to examine longitudinal data even with populations that have high attrition, such as those at end of life, since this data could lead to more effective and better-targeted interventions.

Measures. There is still a need for standardized measures, which are reliable and valid for terminally ill individuals and their family members. Without more standardization it will continue to be difficult to compare results between studies, and to perform meta-analysis studies. Therefore, it is important for future research to begin to standardize measurements when assessing family members who are facing end of life. Since many of the measures used were not originally developed for this population, the accuracy and validity need to also be checked (Chi et al., 2015).

Also, in keeping with Roland's family systems-illness model, broader psychosocial factors of the family and the illness should be assessed, such as familial approaches to dealing with problems, past experiences with illnesses, familial communication patterns, current and recent social supports, stage of the illness, standard progression of the illness, and the family life

cycle. Using this broader perspective in future studies will hopefully find more accurate ways of assessing factors that influence quality of life.

Interventions. Overall the interventions were found to be effective, yet the interventions focused on families were very limited. There are a myriad of psychosocial interventions currently in practice with individuals and their caregivers at end of life (some therapies include: Time-sensitive counseling, narrative therapy, life review, validation therapy, cognitive behavioral therapy, and motivational interviewing). These interventions need to be modified when appropriate, and applied to family systems.

Conclusion

The current research on psychosocial interventions for the family at end of life is promising. Though, as shown, the research in this area which targets the entire family system or even more than one family member at end of life is extremely limited. The majority of the research only focuses on the primary caregiver and the person at end of life without considering the context of the larger family system. As Szinovacz and Davey (2007 & 2013) found, the person who is the primary caregiver often changes over time. Additionally, multiple family members are often involved in the care of ill members. So, the narrow focus of these interventions on only the primary caregiver most likely misses the effects caregiving causes to other members of the family and the family as a whole. Therefore, much more research needs to be done to determine which interventions can have a broader impact to the entire family system. Roland's System-Illness Model would be an appropriate guide for this work. This is especially relevant considering the emphasis currently being placed on the family by palliative and hospice organizations worldwide.

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Table 1. Search Terms and Inclusion Criteria

Search Terms	Inclusion Criteria	Exclusion Criteria
<p>End of life care OR Hospice OR Palliative care OR Terminal* Care</p> <p>AND</p> <p>Family care* OR Informal care* OR Relative* OR Family system* OR Famili* OR Lay care* (to cover caregivers and carers)</p> <p>AND</p> <p>Psychosocial intervention* OR Therapy</p> <p>NOT</p> <p>Medical OR Medication OR Children OR Students</p>	<ul style="list-style-type: none"> • Any psychosocial intervention or therapy • Intervention done before death • Peer reviewed research articles • English language • Origin: United States, Canada, United Kingdom, and Australia • Average age of terminally ill family member aged 45+ years • More than one family member was involved in intervention, measurements, or both 	<ul style="list-style-type: none"> • Interventions done after death • Intervention after death • Medical interventions or studies that looked at effect on medical symptoms (such as pain) • Pharmacological interventions • Technological interventions • Only one family member involved, such as primary caregiver • Study protocols, case studies, and expert/practitioner opinions

Table 2. Overview of Review Articles

Study and location	Sample	Design	Medical Problem	Intervention	Variables and measures	Data collection	Results	Study quality
Chit (2015) Seattle, WA	14 Phase II or III studies on family caregivers at end-of-life	Review	Receiving end-of-life care	Various behavioral and educational interventions	1) Effectiveness found in Educational Interventions 2) Effectiveness found in Behavioral Therapy Interventions 3) Effectiveness found in Psychoeducational Interventions 4) Comparison of three groups	Searched PubMed, CINAHL, Embase, and The Cochrane Library for articles between 2004 -2014	1) Educational Interventions (4 studies): ↑ support (1), knowledge (2), confidence (1), preparedness (1), helpful beliefs (1), and satisfaction with care (1); no change in caregiver's psychological health (2), depressive symptoms (1), perception of symptom control (1) 2) Behavioral Therapy (6 studies): ↑ self-efficacy (1), psychological health (4), QOL (4), hope (1), and problem solving skills (1); no change in caregiver mastery (1), QOL (1), or coping skills (1). 3) Psychoeducational Interventions (4 studies): ↑ intervention rewarding (2), preparedness (2), competence (1), and 1 in both IG & CG 1), less unmet information needs (1), social support (1), qualitative data), Knowledge (1, qualitative data) reduced anxiety (1 found in both IG & CG); no effects found for importance of information (1), unmet needs (1), psychological distress (1), self-efficacy (1 at 5 weeks), competence (1 & 1 at 5 weeks), anxiety (1 at 5 weeks). 4) Comparison of three groups: Each were effective overall; behavioral therapy interventions had more positive outcomes than educational and psychoeducational interventions.	Strengths: Included trends across articles Limitations: Small sample size, potential publication bias
McLean (2007) Canada	5 articles on couples interventions	Review	End-of-life cancer	Various psychosocial interventions	Outcomes for interventions that target couples when one is at end of life	Searched MEDLINE, PSYCHINFO, and CINAHL for articles between 1986 - 2006	<i>Decreased</i> Patients': Negative appraisal of illness (1), psychosocial distress (1), death distress (1), depression (1), negative social support (1) Caregivers': Negative appraisal of illness (1), death distress (1), worry (1), burden (1) <i>Couples'</i> : hopelessness (1), perception of overinvestment/under-benefit (1), perception of inequality (1), distress (1) <i>Increased</i> Patients': Social support (1), QOL (1) Caregivers': Relationship quality (1), Social support (1) <i>Couples'</i> : Perception of overinvestment/under-benefit (1), relationship quality (2)	Limitations: Method section not complete, Small sample of studies, most studies had small sample sizes, G, mixed methods, potential publication bias

Note: Abbreviations included: **QOL** = quality of life; **IG** = Intervention group; **CG** = Control Group; **G** = Generalizability

Table 3. Overview of Psychoeducational Research Articles

Study and Location	Sample	Design	Medical Problem	Intervention	Variables and measures	Data collection	Results	Study quality
Meyers (2011)	476 patient and caregiver dyads (348 IG, 128 CG)	Prospective, multi-institution, randomized clinical trial	Advanced cancer	COPE (Creativity, Optimism, Planning, & Expert Information): Teaches individualized cognitive/behavioral problem-solving	1) <i>QOL</i> : City of Hope QOL Instruments (patients and caregiver versions) 2) <i>Problem-solving abilities</i> : The Social Problem Solving Inventory-Revised Additional measures: Demographics	Baseline Follow-up data collection at 30, 60, 90, 120, and 180 days after randomization.	Patients: 1) <i>QOL</i> : Decline in QOL (6 months) with no difference between IG & CG; significant declines found in psychological and social domains, but not physical or spiritual 2) <i>Problem-solving abilities</i> : All showed a decline (positive & rational problem solving decreased and avoidance increased)	Strengths: RCT, 94% completion rate, checked & accounted for any differences between IG & CG, and sites
United States	Mean patient age: 62 years Mean caregiver age: 61 years						Caregivers: 1) <i>QOL</i> : IG Caregiver's QOL declined at less than half the rate of CG (in psychological, social, and spiritual well-being, but not physical) 2) <i>Problem-solving abilities</i> : no significant changes (decrease in rational problem solving)	Limitations: Excluded people who do not speak English
Midwest of the United States	235 couples (112 IG, 123 CG) Mean patient age: 63 years Mean spouse age: 59 years 84% White	Randomized control trial	Prostate cancer	Family psycho-educational FOCUS Program, (Family Involvement, Optimistic attitude, Coping effectiveness, Uncertainty reduction, and Symptom management)	1) <i>Patient and caregiver QOL</i> : MOS SF-12, FACT-G (vs. 4); FACT-P (patient only) 2) <i>Appraisal variables</i> : 27-item Appraisal of Illness (patient); Appraisal of Caregiving Scale (caregiver); 28-item Mishel Uncertainty in Illness Scale; 20-item Beck Hopelessness Scale 3) <i>Coping</i> : 28-item Brief COPE scale; 17-item Lewis Cancer Self-Efficacy Scale; 32-item Lewis Mutuality and Interpersonal Sensitivity Scale 4) <i>Symptoms</i> : OSQ; EPIC (patient); 4-item spousal version of EPIC (spouse) 5) <i>Risk for distress</i> : 77-item OSQ (Baseline only)	Baseline (before intervention) 4 months after intervention 8 months after intervention 12 months after intervention	Spouses: 1) <i>QOL</i> : IG reported better physical QOL (at 8 & 12 months); IG reported better mental QOL and overall QOL (at 4 months, but not 8 or 12 months) 2) <i>Appraisal variables</i> : IG had less negative appraisal of caregiving, less uncertainty, and less hopelessness (at 4 and 8 months) 3) <i>Coping</i> : IG reported higher self-efficacy (4 & 12 months); better communication; and more active coping (12 months) 4) <i>Symptoms</i> : IC reported less symptom distress; fewer problems with husband's incontinence (4 & 8 months)	Limitations: limited ability to detect moderating effects of stage of illness due to small samples; unable to generalize to patients w/o partners
Northhouse (2007)	134 patient and caregiver dyads (69 IG, 65 CG) Mean patient age: 54 years Mean caregiver age: 52 years Caregivers: 62% husbands	Randomized clinical trial	Recurrent breast cancer	Family psycho-educational FOCUS Program 3 90-minute home visits and 2 30-minute telephone sessions Provided by nurse	1) <i>Appraisal</i> : 27-item Appraisal of Illness (patient); 27-item Appraisal of Caregiving Scale (caregiver) 2) <i>Uncertainty</i> : 28-item Mishel Uncertainty in Illness Scale; 3) <i>Hopelessness</i> : 20-item Beck Hopelessness Scale 3) <i>Coping</i> : 24-item Brief COPE scale 4) <i>QOL</i> : FACT-G (spouse); FACT-B (Patient) 5) <i>Demographics and Medical history</i> : OSQ	Baseline 3 months (following baseline) 6 months	<i>Risk for distress</i> : No moderating factors found <i>Appraisal</i> : IG patients reported decrease in negative appraisal of illness (3 months); IG caregivers reported decrease in negative appraisal of caregiving (3 months) <i>Hopelessness</i> : IG patients reported decrease (3 months), no CG effects found * No effects found in other variables * No effects sustained or found at 6 months Patients who were more ill left study at a higher rate (79% who left, died during the study)	Strengths: RCT, 74% completed, accounted for differences between IG & CG Limitations: English speakers only, potential Type I errors

Kilbourn (2011) United States	29 informal caregivers, 2 from same family Median age of caregiver: 60 years (Patient age not stated) caregivers: 91% female (Race/ethnicity not stated)	One-group, intervention only feasibility study	Hospice patients (48%) Cancer (35%) Neurological condition (17%)	Psycho-educational The Caregiver Life Line (CaLL), a telephone-based program that provided coping skills training, cognitive-behavioral strategies, and positive benefit finding 10 to 12 semi-structured calls Delivered by master level counselor	1) <i>Depression</i> : CES-D 2) <i>Stress</i> : PSS 3) <i>QOL</i> : MOS-SF-36 4) <i>Perceived social support</i> : ESS1 5) <i>Benefit finding</i> : BFS 6) <i>Ability to use adaptive coping skills</i>	Baseline 3 months 6 months	1) <i>Depression</i> : Decreased over time 2) <i>Stress</i> : Decreased over time 3) <i>QOL</i> : Emotional/social QOL increased from pre- to post-intervention; physical QOL decreased over time 4) <i>Perceived social support</i> : Increased from pre- to post-intervention 5) <i>Benefit finding</i> : Increased from pre- to post-intervention 6) <i>Ability to use adaptive coping skills</i> : high levels reported at end	Strengths: Managed consistency of intervention Limitations: Small sample size, G, no CG, somewhat high attrition (32%), excluded non-English speakers
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Note. Abbreviations included: **CG** = Control group; **DCBGA** = Data collectors blinded to group assignment; **G** = Generalizability; **IG** = Intervention group; **IRB** = Institutional review board; **IRIC** = Internal reliability of instruments checked; **QOL** = quality of life; **RCG** = Randomized Control Group; **SAI** = separate assessors and interventionists; **SM** = Statistical methodology; **UEI** = Used established instruments.

Measure abbreviations: **BFS** = Benefit Finding Scale; **BMMRS** = Brief Multidimensional Measures of Religion and Spirituality; **CES-D** = Center for Epidemiological Studies-Depression scale; **COPE** = Coping Orientations to Problems Experienced; **ESS1** = ENRICHID Social Support Instrument; **FACT-B** = Functional Assessment of Cancer Treatment – Breast Cancer; **FACT-G** = Functional Assessment of Cancer Treatment – General; **FACT-P** = Functional Assessment of Cancer Treatment – Prostate; **MBPC** = Memory Behavioral Problem Checklist; **MOS SF-12** = Medical Outcomes Study 12-item short form; **MOS SF-36** = Medical Outcome 36-item Short-Form Health Survey; **MBPC** = Memory and Behavior Problems Checklist; **OSQ** = 16-item Symptom Scale of the Omega Screening Questionnaire; **PSS** = Perceived Stress Scale; **RDAS** = Revised Dyadic Adjustment Scale

Table 4. Overview of Therapy Research Articles

Study and location	Sample	Design	Medical Problem	Intervention	Variables and measures	Data collection	Results	Study quality
Roth (2005) New York, United States	312 spouses who had at least one other family member in area (163 IG, 149 CG)	Randomized Control Trial	Alzheimer's disease	Counseling and support intervention Three components: 1) 2 individual and 4 family counseling sessions 2) Caregiver support group 3) Ad hoc telephone counseling Provided by counselors with advance degrees in social worker or related fields	1) <i>Social support</i> : Size and extent of social network, caregiver's Satisfaction with the Social Support Network; caregiver report of frequency of receiving information and assistance from support persons 2) <i>Symptoms of depression</i> : Geriatric Depression Scale 3) <i>Caregiver stressfulness appraisals</i> : MBPC Additional measures: Demographics	Baseline (before intervention) 12-month assessment	Intervention group: ↑ Social support ↓ Depression ↑ Caregiver stress Through structural equation modeling (SEM) determined that caregiver satisfaction with social support was a significant predictor of their perceived stress and depression.	Strengths: RCG, sample size, 73.4% completion rate Limitations: Possible treatment diffusion; unknown which of 3 components was most effective; original measures not directly designed for variables
Allen (2008) Southeast United States	31 dyads (17 IG/14 CG) Mean patient age: 75 years Mean caregiver age: 56 years Caregivers: 83% female 71% African American	Randomized, controlled group	Life limiting illness or chronic medical problem	Legacy projects: a brief, life review intervention Intervention: 3 sessions (averaging 82 minutes, 66 minutes, & 70 minutes) Contact Control: 3 phone calls (averaging 16 minutes, 13 minutes, & 14 minutes)	1) <i>Caregiver stress</i> : Caregiver Stressors Scale-Revised 2) <i>Caregiver depression</i> : CES-D 3) <i>Caregiver perception of ill person's symptoms</i> : Physical Self-Maintenance Scale and IADL Measures, ESAS, additional scaled questions 4) <i>Caregiver religiosity/spirituality</i> : BMMRS 5) <i>Patient's reported physical symptoms</i> : ESAS. Additional symptom assessment 6) <i>Patient's interactions</i> : Talkativeness measure in symptom assessment 7) <i>Patient's depression</i> : CES-D 8) <i>Patient's subjective well-being</i> : 3 scaled questions 9) <i>Patient's meaning based coping</i> : BMMRS Additional measures: Demographics Cognitive impairment (MMSE), to 10 impaired individuals Project Evaluation Survey	Baseline (before intervention) Time 1 assessment (approx. 1 week after intervention)	1) <i>Caregiver Stress</i> : Reduced compared to control group 2) <i>Caregiver depression</i> : Reduced compared to control group 3) <i>Caregiver perception of ill person's symptoms</i> : Increased talkativeness versus control; no change for estimates of pain, tiredness, nausea, drowsiness, decrease appetite, weight loss, or breathing difficulties 4) <i>Caregiver religiosity/spirituality</i> : No changes 5) <i>Patient's reported physical symptoms</i> : decreased breathing difficulty and pain; no change in agitation, tiredness, nausea, drowsiness, appetite, or weight loss. 6) <i>Patient's interactions</i> : Increase in talkativeness versus control 7) <i>Patient's depression</i> : Reduced symptoms versus control 8) <i>Patient's subjective well-being</i> : no difference 9) <i>Patient's meaning based coping</i> : increased sense of religious meaning in intervention group; control had increased daily spiritual experiences versus intervention group	Strengths: RCG, SAI Limitations: G
McClean (2008) Toronto, Canada	16 couples Mean age: 48 years (Sex & race not included; 88% English speakers)	Pilot study One-arm, pre- and post-intervention, prospective design	Advanced cancer	Emotionally focused couples therapy There was an average of 12 sessions completed	1) <i>Marital functioning</i> : 14-item RDAS 2) <i>Depression</i> : Beck Depression Inventory-II 3) <i>Hopelessness</i> : Beck Hopelessness Scale 4) <i>Satisfaction and benefits</i> : Questionnaire developed by researchers Additional measures: Medical and demographic information	Baseline After 4 sessions After 8 sessions 3 mo. after intervention	1) <i>Marital functioning</i> : Improved over time 2) <i>Depression</i> : No difference over time or by gender; difference between baseline and last esp. for patients. 3) <i>Hopelessness</i> : No change 4) <i>Satisfaction and benefits</i> : Majority satisfied & found intervention beneficial Number of sessions (from 8-22) had no effect	Strengths: 94% retention Limitations: excluded non-English speakers, G

Study	Participants	Intervention	Comparison	Outcomes	Findings	Strengths	Limitations	
Hall (2013)	29 patients (14 IG & 15 CG), and 9 IG family members	Qualitative, Phase II RCT	Advanced cancer	Dignity therapy	Participants' perceptions of benefits on dignity therapy	Baseline 1 week 4 weeks (Qualitative assessment)	Findings: * Appreciated generatively document (7 IG, 3 FIG) * Generatively document was incomplete (6 IG, 5 FIG) * Felt they were same person (IG 4, CG) * Maintained pride (IG 5; CG 1, FIG 3) * Hopefulness (IG 6, CG 8, FIG 2) Attitude/Major others interact with patient (IG 6, CG 8, FIG 2)	Strengths: ECA, adherence to intervention protocols checked Limitations: Small sample size, high attrition (47%), family of CG were not included
MacClement (2007)	60 family members	Qualitative Study	Cancer (97%), and non-malignant conditions (3%)	Dignity Therapy	Perceptions of dignity therapy by family members who received generative documents created by their deceased relatives before their death	Patient demographics at start of study	Key Findings from family members responses: * Helped patient (95%) * Recommend to others (95%) * Patient's sense of dignity was increased (78%) * Helped family after death (78%) * Will continue to comfort family (77%) * Increased patient's sense of purpose (72%) * Helped patient prepare for death (65%) * As important as other parts of patient's care (65%) * Reduced patient's suffering (43%)	Strengths: Spoke of ethical issues Limitations: time length of intervention not included, G, no CG
Canada and Australia	Mean family member age: 55 years 77% female (patient age & race not included)			Intervention done with patient before death, in 28% of interviews 1 or more family member was present (in total 19 family members)				

Note: Abbreviations included: **CG** = Control group; **DCBGA** = Data collectors blinded to group assignment; **ECA** = Ethics Committee Approval; **G** = Generalizability; **IG** = Intervention group; **IRB** = Institutional review board; **IRIC** = Internal reliability of instruments checked; **QOL** = quality of life; **RCG** = Randomized Control Group; **SAI** = separate assessors and interventionists; **SM** = Statistical methodology; **UEI** = Used established instruments.

Measure abbreviations: **BFS** = Benefit Finding Scale; **BMMRS** = Brief Multidimensional Measures of Religion and Spirituality; **CES-D** = Center for Epidemiological Studies-Depression scale; **ESAS** = Edmonton Symptom Assessment Scale-Modified; **ESSI** = ENRICHD Social Support Instrument; **FACT-B** = Functional Assessment of Cancer Treatment – Breast Cancer; **FACT-G** = Functional Assessment of Cancer Treatment – General; **FACT-P** = Functional Assessment of Cancer Treatment – Prostate; **MBPC** = Memory Behavioral Problem Checklist; **MOS SF-12** = Medical Outcomes Study 12-item short form; **MOS SF-36** = Medical Outcome 36-item Short-Form Health Survey; **MBPC** = Memory and Behavior Problems Checklist; **OSQ** = 16-item Symptom Scale of the Omega Screening Questionnaire; **PSS** = Perceived Stress Scale; **RDAS** = Revised Dyadic Adjustment Scale

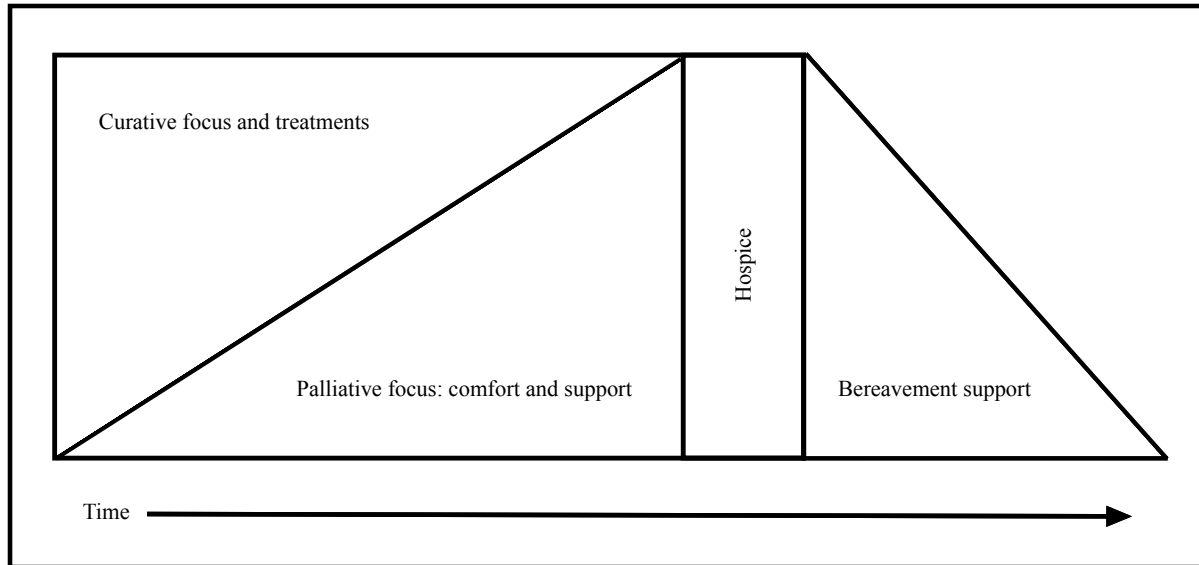


Figure 1. Relationships Among Curative, Palliative, Hospice, and Bereavement (adapted from Ersek & Farrell, 2005, p. 47)

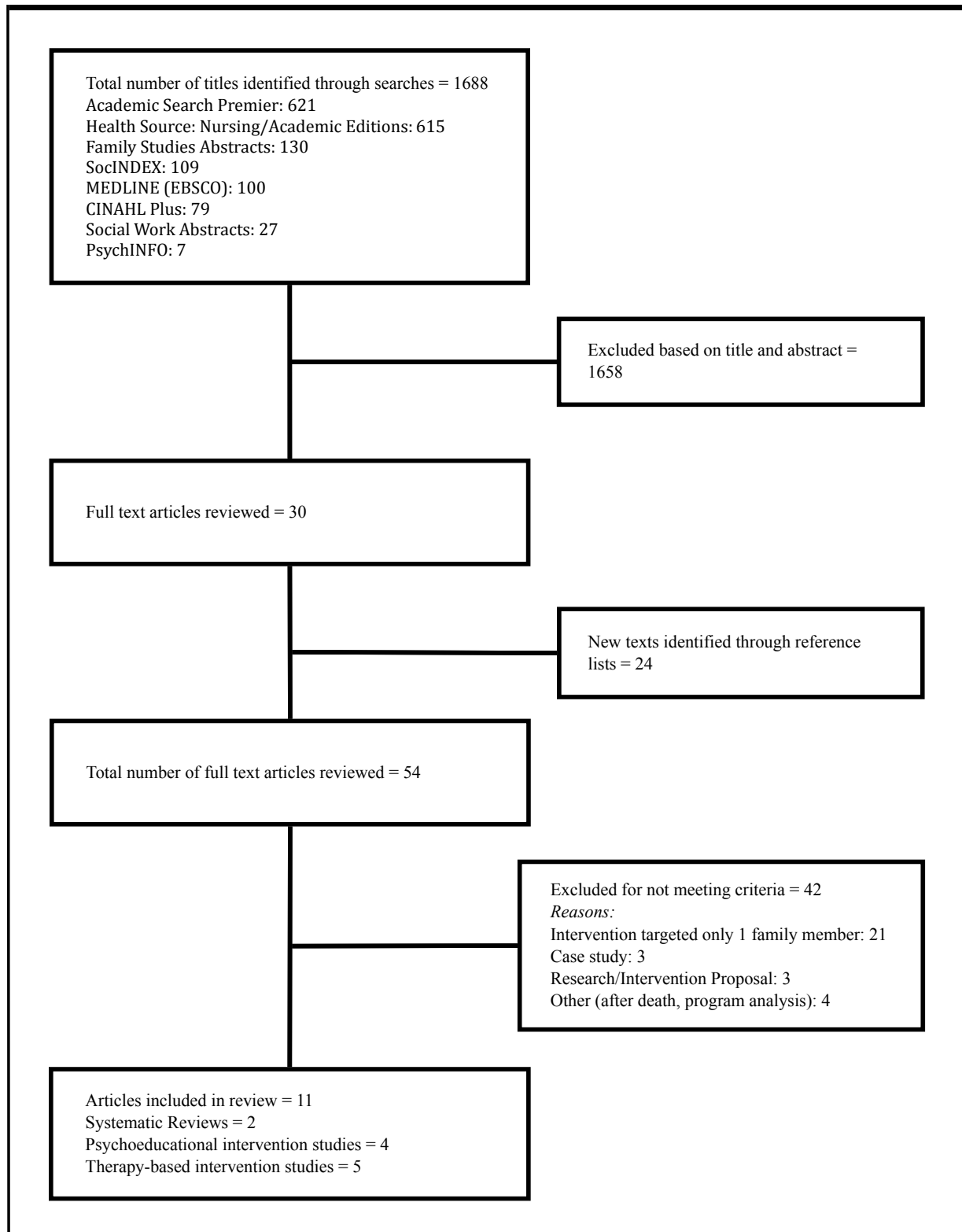


Figure 2. Outline of article selection process

Appendix A

Article Analysis Form

Denise Johnson
Article
Research aim, questions(s) and/or hypothesis(es) (include research criteria)
Independent variable(s) and operational definition(s); how measured and reliability of the measure(s)
Dependent variable(s) / and operational definition(s); how measured and what is the validity and reliability of the measure(s)
Control or intervening (modifying) variables (specified or not)
Sample - type, how constructed, size, location, type of care, and characteristics
Data collection - methods and procedures (how, when, where, and by whom were data collected; study quality standards).
Type of research design (name specific design). What are issues regarding the validity of design (consider the internal validity)?
Purpose of the research
Data analysis - list the statistics used in data analysis
Findings, results, or outcomes of the research
Conclusions (external validity of the study; any issues about the research which lead you to question the validity of the findings)
Ethical issues and safeguards (specified or not)
Practice implications
Policy implications
Research implications and next logical research steps (re: questions; hypotheses; methods)

Limitations - author's(s') critique of this research
Your critique of this research (include overall rating of strength and applicability)

Form A. Article analysis form used to extract the data from found research articles.