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Interventions to Alleviate the Psychosocial Needs of Hospice Family Caregivers: A Systematic Review

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MSW Clinical Research Proposal

Presented to the Faculty of the
School of Social Work
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In Partial fulfillment of the Requirements for the Degree of
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.

Abstract

Hospice care is a growing service to individuals with terminal and chronic illnesses to promote quality of life and comfort versus treatment at the end of their life. The support of hospice care extends to the family of hospice patients. Many patients who wish to receive hospice care at home have involvement from family to become their primary caregiver. This systematic review was designed to answer the question, what interventions are available to alleviate the psychosocial needs of hospice family caregivers. Based on the inclusion and exclusion criteria set for this study 11 articles met criteria to be analyzed. Two major themes emerged from the data, counseling services, and education opportunities that was further broken down into informal education and psychoeducation. Further research should continue to explore effective interventions for hospice family caregivers.

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Introduction

Hospice care is available to individuals with a terminal illness and their family members when the choice is made to focus on comfort and quality over quantity of life. According to the National Hospice and Palliative Care Organization (2013) (NHPCO), hospice care is a growing utilization. It is estimated that the number of people choosing to access hospice care in 2012 was between 1.5 and 1.6 million, either in their home or in a facility. Family members often become the patient's primary caregiver when receiving hospice at home (Robinson & Segal, 2016). The family caregiver, may become responsible for providing physical care to the patient when they are no longer able to care for themselves and manage the medications that are provided under hospice care. Along with managing the needs of the family member on hospice, the family caregiver also has their own psychosocial needs to address.

Services exist in the community to alleviate the psychosocial needs of family caregivers. By working with the interdisciplinary hospice team, coordination of the appropriate services can be achieved (Kovacs, Bellin, & Fauri, 2005). The challenge that has been presented through the research is that family members have been reluctant or unable to examine their own needs as all attention is focused on the care of the family member on hospice (Jack, O'Brien, Scrutton, Baldry, & Groves, 2014). Through a systematic review, this research study intends to examine interventions available to alleviate the psychosocial needs of hospice family caregivers.

Background

Hospice Care, in the United States, is a program that developed in the 1970's to address the needs of individuals with a terminal illness who wanted to die in their home and focus on comfort versus treatment (Kovacs et al, 2005). The mission of hospice services has been described as providing palliative care to people, who have a life expectancy of 6 months or less

from a terminal illness, by adding quality to what life is left (Robinson & Segal, 2016). Hospice care has also been described as, “focusing on caring, not curing” (National Hospice and Palliative Care Organization, 2012, p. 3). According to the World Health Organization, a palliative care approach is intended to improve an individual’s quality of life, who are facing a life threatening or chronic illness by using a team approach to assess and treat pain as well as other emotional and physical symptoms. From the early developments to this point in time, hospice care for patients has been a growing service provided to individuals nearing the end of their life wherever they call home (e.g. private residence, hospice facility, or nursing home). According to the NHPCO (2012) research, the number of people receiving hospice services tallied to roughly 1.65 million individuals in 2011. Further data from NHPCO (2012) showed that in 2001 only 18.8% of all Medicare decedents accessed hospice services for three or more days. Those numbers increased in 2007 to 30.1% of all Medicare decedents having accessed hospice services for three or more days (National Hospice and Palliative Care Association, 2012).

Hospice care provided by family members

Individuals who choose to remain at home while receiving hospice care are primarily taken care of by a family member acting as the primary caregiver (Robinson & Segal, 2016). The primary caregivers, also known as family caregivers, take on the task of providing everyday care and medication management to the patient under the supervision of a hospice interdisciplinary team (Robinson & Segal, 2016). Just as the interdisciplinary team (e.g. doctor, nurse, social worker, chaplains, nursing assistants) guides the family caregiver in medications and physically caring for the hospice patient, the interdisciplinary team addresses the emotional needs and helps reduce anxiety for the Patient’s caregivers (Jack et al., 2014). As part of a hospice team, home

health aides and other personal care assistants can be brought into the home to supplement cares being done by family members, though for most hospice patients, care is primarily given by the family members.

Current research has shown that some hospice patient's wish to be at home while on hospice, though are not at their home for various reasons that often relate to family involvement (Broom & Kirby, 2012) while the NHPCO (2012) stated that, "in 2011, 66.4% of hospice patient's received care at home" (p. 6). Various studies have presented issues families and patients have expressed regarding hospice care at home (Kovacs et al., 2005; Kehl, Kirchoff, Kramer, & Hovland-Scafe, 2009; Krug, Miksch, Peters-Kimm, Engeser, & Szecsenyi, 2016). From hospice patients' perspective, reasons for not receiving hospice services at home circulated around the concerns about family members' capacity to cope and releasing family from the stress associated with being a caregiver through the dying process (Broom & Kirby, 2012). Studies showed many common themes found within research regarding caregiver's needs with family members on hospice (Kehl et al., 2009; Harrop, Byrne, & Nelson, 2014). Several of these concerns expressed by family caregivers were: lack of individual competence for providing care, inability to recognize their own needs (both physical and emotional), and the ability to cope with the dying process (Jack et al., 2014; Harrop et al., 2014).

While family members step up by providing care for individuals living at home on hospice, research shows that many family caregivers have their own concerns for the patient's wellbeing as well as their own wellbeing (Aoun et al., 2015). Harrop et al. (2014) discussed that family members are often the ones (on a day to day basis) assessing symptoms and managing medications accordingly for the family member on hospice. "When hospice patients are discharged back home families often express concerns as they themselves receive no formal

training or guidance on the practicalities of physical care, instead adopting a ‘trial and error approach to palliative care’ (Harrop et al., 2014. np). Jack et al. (2014) expressed that family caregivers felt reluctant to ask for help or felt that services were unavailable to them while currently caring for their loved one.

The unpreparedness of family caregivers extends past the Western world. Joad, Mayamol, & Chaturvedi (2011) researched in India, what the informal caregiver of a terminally ill cancer patient needs. Joad et al. (2011) results coincided with research done in Western parts of the world, including the United States that informal caregivers are unprepared for the physical and psychosocial challenges they will face at home. “Providing appropriate support to address caregivers’ needs can ensure better quality of care for the patient and family unit as well as improve psychological outcomes for caregivers in the long run” (Aoun et al., 2015, p. 509). Joad et al. (2011) described that when family members are not acknowledged as a vital part to the well-being of the individual, the needs of the family caregivers go unnoticed. By doing this, the hospice individual is being denied the chance to be cared for by well prepared (emotionally, mentally, and physically) family members.

Current support for family caregivers

Several forms of support are available in the community to address the range of needs experienced by family caregivers of hospice patients. Current services available to family caregivers presented in the research include: providing education regarding medication, movement, and physical assistance to patients and their safety to ease caregivers concerns (Kovacs et al., 2005). Kovacs et al. (2005) also caution the amount of information and what information is provided at times as this may be overwhelming and not useful to the caregiver depending on where they are at in their own grieving process. Support groups for family

caregivers and respite stays are common support options that family caregivers will utilize to maintain their own self-care (Robinson & Segal, 2016). Respite care can be defined as alternative care available for someone, ranging from a day to several weeks, when the family caregiver needs time away from being a caregiver (Administration on Aging, 2010). According to Jack et al. (2014) burial services, advanced directives, and after death resources are available, though little knowledge is known about what tools are needed for caregivers during the dying process as families have been reluctant to address their own needs focusing all attention on the needs of the patient.

Research has shown that there is a need to support the family caregivers of hospice patients as this in return benefits the overall well-being of the hospice patient. Services are available to assist families during the dying process, though the dilemma remains that often time's family caregivers may be unable to identify their own psychosocial needs while working towards fulfilling the psychosocial needs of their family member on hospice. By conducting a systematic review, research is pulled and examined systematically to determine the best available interventions out of the research that already exists.

Methods

Research Purpose

The purpose of this systematic review was to explore the question: what interventions are available to alleviate the psychosocial needs of hospice family caregivers? For this study, psychosocial was defined as the psychological and social needs of an individual that can include mental, physical, emotional, spiritual, or financial need (World Health Organization, nd.). This systematic review gathered and analyzed empirical peer reviewed articles to determine what interventions do exist for hospice family caregivers. Both qualitative and quantitative articles

were included to gather all empirical information available. The process of collecting data for this study entailed a specific search strategy and a set of inclusion criteria to determine what articles were kept and rejected.

Inclusion Criteria

The set of inclusion criteria for this study were as follows: all articles analyzed for this systematic review were empirical peer reviewed studies. Both qualitative and quantitative articles were considered for this study. The time frame articles were pulled from was 2000 to present as research has shown a growth both within the amount of people receiving hospice services and the recognition to implement services that support patient and families' psychosocial needs (Connor, 2007). No specific sample size was required for the articles analyzed as this study aimed to examine interventions available to alleviate the psychosocial needs of hospice family caregivers. No specific hospice diagnosis was needed and no specific time frame for how long a person was under hospice care was needed for this study.

Articles that were qualified to be extracted from the databases for this study had subjects that were family caregivers of hospice patients providing care at the time of the study. The focus of this study was interventions available to alleviate hospice family caregivers psychosocial needs; therefore, articles had to address the psychosocial needs of the hospice family caregivers and not the psychosocial needs of the patient. The articles had to discuss interventions that were used to assist those family caregivers in addressing or alleviating their own needs. The subjects of the articles were family caregivers of hospice patients and that hospice care was happening in a home environment. The individual receiving the hospice services was 50 or older. No articles that had a sample of children receiving hospice care and being cared for by their parents were considered for this study.

Exclusion Criteria

Fourteen of the 25 articles that initially were thought to qualify for this study were excluded as they did not pertain to the research question or the set of inclusion criteria. These articles were excluded once the methods and findings sections were read. Reasons for exclusion included support that was explored for bereaved family members instead of support while the family member was providing care. The majority of articles looked for interventions to alleviate the patients' needs through the use of a caregiver. These studies measured the effects of the interventions on patient's psychosocial needs, and not on psychosocial needs of the caregiver.

Search Strategy

In a preliminary search of journal articles little to no data was found addressing the question of what interventions are available to identify the psychosocial needs of hospice family caregivers. To understand the scope of available literature on the topic of psychosocial needs of hospice family caregivers, the research question was altered to: what interventions are available to alleviate the psychosocial needs of hospice family caregivers?

Electronic databases used for the extraction of studies for this review were Social Work Abstracts, SocINDEX, Google Scholar, Family Studies Abstracts, PubMed, PsycINFO, and Summon 2.0 through the University of St. Thomas and St. Catherine University. The following keywords were used in combination: caregivers, family caregivers, informal caregivers, caregiver burden, hospice at home, hospice care, hospice, palliative care, psychosocial needs, psychosocial factors, psychosocial, psychosocial readjustment, and psychosocial rehabilitation.

Data Abstraction and Analysis

For initial gathering of data all abstracts were read to determine if criteria was likely to be met for consideration of this review. All data that did not meet criteria during abstraction was

dismissed. To determine the second cut of data, all methods and findings sections from the articles initially gathered were carefully examined and determined eligible or ineligible for this study based on the inclusion criteria set. A record was kept of the number of articles that were eligible for this study and the number of articles ineligible for the study once the initial gathering of data was complete. A total of 25 articles were considered for this study based on the abstract. Following the methods and findings section review, 11 articles met all inclusion criteria for this study.

The remaining 11 qualifying articles after the second cut were analyzed to create themes. Thematic organization of the articles included: type of method used, intervention implemented and the findings from each article. The same interventions were paired and recorded if the same outcomes were present. Size and type of each study sample was also taken into consideration and discussed if it was pertinent to the type of intervention used. Gaps in the research were also recorded and discussed for future areas of research needed and social work implications.

Findings

Through analysis of the literature, two themes emerged out of what interventions are available to alleviate psychosocial needs of hospice family caregivers. The themes include 1) grief counseling services; 2) education opportunities. Two subthemes emerged from education opportunities. For a theme to be present in the data more than one article had to utilize similar interventions. No article addressed psychosocial as a whole, but focused on key aspects related to psychosocial functioning such as perception of quality of life, competence, caregiver burden, and stress. Table 1 lays out each article that met inclusion criteria organized by the themes they fell under.

Counseling Services

Two of the eleven articles discussed the implementation of counseling services to hospice family caregivers to alleviate factors associated with the emotional toll hospice caregivers can experience (Flanagan-Kaminsky, 2013; Kilbourn et al, 2011). For both studies, the counselors focused on offering emotional support and ways to manage stress related to caregiving.

Flanagan-Kaminsky (2013) found that counseling intervention took place in the home and did not have set topics that would be discussed each visit rather each visit with the counselor was open to discuss whatever thoughts were present; while Kilbourn et al. (2011) implemented a CaLL intervention program where each counseling session was held over the phone and had a topic to be discussed ranging from self-care to grief and loss to communication with the patient. Following the implementation of this intervention, post-test and caregiver feedback showed caregivers increase in quality of life (QOL), decrease in stress, and increase in sense of competence (Flanagan-Kaminsky, 2013; Kilbourn et al, 2011).

Education Opportunities

Various forms of education interventions rose from the data as ways to alleviate psychosocial needs for hospice family caregivers. The two subthemes were created, 1) informal education, and 2) psychoeducational programs, based on the data extracted from the articles.

Informal Education. Four of the eleven articles focused on providing education to informal caregivers to decrease their anxiety and increase their competence of being in the caregiving role. The informal education caregivers received was focused on ways to manage the patient's symptoms that would in return alleviate the concerns from the caregiver. These education sessions were spontaneous and had no set agenda for what was to be discussed. Education regarding medication administration was provided by the hospice nurse during regular

visits while the caregiver continued to provide care and the nurse was present to observe and talk through the medication administration and assessment (Cagle & Kovacs, 2011; Moody et al., 2004; Washington, 2011; and Wittenberg-Lyles et al., 2012). Hands-on education also focused on assessing symptoms of discomfort and natural progression of the disease. Washington (2011) and Wittenberg-Lyles et al. (2012) required no specific hospice diagnosis for their study while Cagle & Kovacs (2011) and Moody et al. (2004) required hospice patients to have a cancer diagnosis with Moody et al. requiring the cancer diagnosis to be specifically lung cancer. Responses were gathered from the family caregivers through interviews at multiple points during the study. Participants voiced their appreciation for the hospice nurse in providing education on caregiving during their visits, and noted they felt an increased sense of competence and reduced anxiety with administering medication and identifying symptoms associated with distress and progression of the disease (Cagle & Kovacs, 2011; Moody et al., 2004; Washington, 2011; Wittenberg-Lyles et al., 2012).

Psychoeducational Programs. Three of the eleven articles discussed the use of structured psychoeducational programs with the intent to reduce stress, anxiety, increase a sense of competency, and increase a sense of quality of life for the caregiver. Hudson & Aranda (2014), Hudson et al. (2008), and Leow et al. (2015) studied the effects of a psychoeducational program for hospice family caregivers. All three studies required a hospice diagnosis of cancer. Topics within the psychoeducation program that were present in all three studies included taking care of yourself, what it means to be a caregiver, signs of stress and coping strategies, education of progression of a terminal illness, and identifying signs that death is near and how to talk to family about this. Both Hudson & Aranda (2013) and Leow et al. (2015) created one on one psychoeducation provided by a hospice nurse. Hudson & Aranda (2014) also conducted a group

psychoeducation group of different participants than the one on one program. Hudson et al. (2008) conducted their study using a group psychoeducation program. All three studies showed the same results that after completing the psychoeducation program, the majority of participants found it helpful in reducing anxiety, increasing their quality of life, and competence as being a caregiver (Hudson & Aranda, 2014; Hudson et al., 2008; Loew et al., 2013).

Two separate articles that met all inclusion criteria, but did not pull up as a theme, were: assisting family caregivers to provide direct care to the hospice patient, with the second article having discussed teaching caregivers to utilize problem solving skills. Empeño et al. (2013) interviewed hospice family caregivers regarding what the caregiver felt was most beneficial in the services they received to alleviate feelings of caregiver burden. The majority of respondents acknowledged that assistance with providing direct care to the patient was most beneficial in alleviating caregiver burden as they were able to focus on self-care techniques. Participants voiced that the help of another person providing care for periods of time allowed them to tend to household chores and get adequate amounts of sleep (Empeño, 2013).

The second article that met all inclusion criteria but did not meet criteria to become a theme was McMillan et al. (2005). McMillan et al. (2005) studied the implementation of coping skills through the COPE Model to hospice family caregivers as a way to reduce caregiver burden and increase in quality of life. The coping skills intervention was taught by the intervention hospice nurse in one on one meetings with the caregiver. Following the completion of a post test, the group that received the coping skills intervention reported improvement in quality of life and reduction in feelings of caregiver burden compared to the pretest and compared to the control group. (McMillan et al., 2005).

Table 1: Included Articles

Theme	Author(s)	Sample	Intervention	Findings
Counseling Services	Flanagan-Kaminsky, D. (2013)	VA contracted hospice program	In person 1:1 counseling services	Offered emotional support, increase in QOL, competence, decrease stress
	Kilbourn, K.M., Costenaro A., Madore, S., DeRoche K., Anderson, D., Keech, T., & Kutner J.S. (2011)	7 hospice agencies; 19 participants	CaLL intervention	Decrease in depression/stress, increase in emotional support & QOL
Education Opportunities: Informal Education	Wittenberg-Lyles, E., Demiris, G., Oliver, D.P., Washington, K., Burt, S., & Shaunfield S. (2012)	Hospice agencies in western U.S. 81 hospice caregivers, mean age 61	Education during regular hospice visit	Increased feeling of competence, reduces anxiety
	Washington, K. (2011)	15 hospice caregivers	Education learning/doing	Decrease anxiety, increase competence & knowledge
	Cagle J.G. & Kovacs P.J. (2011)	69 caregivers, large gulf coast hospice agency	Education during visits	Increase competency, reduces anxiety & stress
	Moody, L.E., Webb, M., Cheung, R., & Lowell J. (2004)	6 caregiver participants, hospice patient: dx lung cancer	Caregiver focus group	Increase competence and knowledge
Education Opportunities: Psychoeducational Programs	Hudson, P., Quinn, K., Kristjanson, L., Thomas, T., Braithwaite, M., Fisher, J., & Cockayne M. (2008)	6 hospice programs, Victoria Australia 44 participants	Psychoeducation group	Increase competence, decrease stress, increase QOL
	Hudson, P., & Aranda, S. (2014)	Group 1: 300 participants Group 2: 156	Group 1: 1:1 psychoeducation programme Group: 2 psychoeducation group	Improvement in competence and reduce stress/anxiety
	Leow, M., Chan, S., & Chan, M.F. (2015)	4 Singapore hospice programs	Psychoeducational intervention 1:1	Higher QOL, lower stress
Outliers	McMillian S.C., Small B.J., Weitzner, M., Schonwetter, R., Tittle, M., & Haley, W.E. (2005)	Control group 354 caregivers; intervention group 109	COPE intervention	Improved QOL, reduced caregiver burden
	Empeño J., Raming, N.T.J., Irwin, S.A., Nelesen, R.A., & Lloyd, L.S. (2013)	182 caregivers	Direct care, transportation services, housekeeping, meals	Direct care highest received in alleviating stress

Limitations

One significant limitation to this study is the available data that focuses on the needs of family caregivers. From the set of inclusion criteria implemented, only 11 articles were extracted. Research focus on hospice family caregivers is still relatively new to the western world as healthcare continues to shift to family centered focus. This study only focused on hospice patients that were being cared for by a family member in a home. Expanding the search criteria by time or age of hospice patients may retrieve more results than this study presented on.

Discussion

This systematic review sought to examine studies on interventions that alleviate psychosocial needs of hospice family caregivers. Findings from the studies that met inclusion criteria for this systematic review suggested that counseling services, informal education on patient care, and psychoeducational programs for the caregivers were beneficial in reducing symptoms of caregiver burden and stress, while also increasing quality of life and a sense of competence. No article that met all inclusion criteria focused on measuring psychosocial needs as a whole, rather, each study focused on a particular issue related to psychosocial well-being such as stress, quality of life, or competence.

Implications for Social Work Practice

Much of the studies focused on hospice nurses providing the interventions rather than social workers. Clinical social workers could prove to be highly useful in the delivery of some of these interventions discussed in the findings such as counseling services and psychosocial education. Clinical social workers are trained to think within the bio-psychosocial-spiritual framework when working with individuals. Social workers often connect individuals with

services in the community so hospice social workers would be ideal in assisting family members to identify their needs.

Implications for Policy

Focus on the importance of the wellbeing for the family caregiver of hospice patient's is still a new concept being implemented across western healthcare. Research is beginning to show the benefits of providing services to maintain the mental health of the caregiver as the wellbeing of the caregiver affects the wellbeing of the hospice patient. Policies should be explored both at the agency and government level of funding services that have shown to be beneficial in alleviating the psychosocial needs of hospice caregivers and making those services easily accessible for individuals that may be limited financially and mobility.

Implications for Research

This study initially aimed to examine interventions available to identify the psychosocial needs of hospice caregivers since research has shown that hospice caregivers often have difficulty identifying what their individual needs are as so much of their attention is focused on the needs of the patient. (Jack, O'Brien, Scrutton, Baldry, & Groves, 2014) As minimal research initially was found that studied ways to identify psychosocial needs for caregivers, future research should focus on useful tools available and the development of tools that would help the caregiver identify their psychosocial needs.

Further research should continue to be explored in effective interventions to alleviate psychosocial needs of hospice family caregivers. The majority of interventions discussed in this study focused on education for the self-care of the caregiver or education on caring for the patient to alleviate the concerns expressed by caregivers. Little research was found on the effects of the implementation of counseling services. As only two studies that met criteria were found

that examined the use of counseling services to caregivers; further research should continue to be explored on the effects of counseling services. Only one article was found that studied implemented problem solving skills as an intervention for family caregivers. Meeting the needs of the caregivers has shown to be just as important as meeting the needs of the patient in fulfilling the patient's wishes of remaining in their home during the dying process.

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