



**FAMILY CAREGIVER EMPLOYMENT: AN EXPLORATION OF CAREGIVER
AND HOSPICE NURSE COMMUNICATION**

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ABSTRACT

Family caregivers (FCGs) are among the most key elements of hospice care, providing care around the clock when nurses or other allied health professionals are unable. FCGs prove important to the overall comfort of the patient during the last days. They provide emotional support, administration, and help with day to day activities (Schulz & Eden, 2016).

Over the past several decades the healthcare system has seen a decrease in the number of FCGs relative to the demand. This increase in demand can be attributed to both an increase in the number of older adults, and advancements in science and medicine. The decrease in supply of FCGs can be partially attributed to an overall increase in the percentage of women in the workforce (Levine, 2003). Currently more than half of family caregivers are employed, and it is expected that this number will continue to rise, causing a further disruption in the supply and demand of FCGs (Longacre, 2017).

Currently the average working caregiver will spend 85-253 hours per month providing assistance to an older adult (Schulz & Eden, 2016). This number is contingent upon the functionality and amount of activities of daily living (ADLs) that the older adult is able to complete on their own. The more needs an older adult has, the more time the FCG will spend caregiving (Schulz & Eden, 2016).

During the time in which the family caregiver is caring for the individual they are likely to experience an increase in negative psychological effects. These effects can result in decreased care for the patient, have financial implications, and cause further physical and emotional health issues. Psychological effects often experienced are stress, anxiety, and depression. The longer family caregivers are engaged in care the more likely they are to experience anxiety and depression (Longacre, 2017). These negative effects are exacerbated by stresses of work and a limited amount of time, putting the working caregiver at an increased risk of experiencing negative effects. In order to provide a holistic type of care for the older adult during the final days of life, it is important that the hospice nurse assess not only the patient, but also the family caregivers' needs. In particular, it is critical that the nurse evaluate the demand of the FCGs work and the impacts it has on caregiving. Some examples of these are the availability of the FCG to the hospice patient in emergent situations, financial loss due to time off work, and stresses resulting from caregiving (Longacre, 2017).

The goal of this research was to discover the strategies nurses use in order to help assist full-time employed FCGs who are caring for cancer patients enrolled in hospice. The data used for the current study is derived from the parent project conducted by Ellington and colleagues. We reviewed 70 transcripts of hospice nurse-family caregiver interactions during hospice home visits for cancer patients and their families. Each transcript was reviewed coded. Twenty-nine of the participating FCGs were employed full-time or part-time, and 34 visits where employment conversations occurred between nurses and caregivers. The objectives of the research were to:

1. Determine if the nurse initiates conversation with the FCG about the FCG's personal needs and stresses.
2. Determine whether the FCG initiates conversation about their own personal needs and stresses.
3. Ascertain whether the nurse offers assistance to the FCG based on the needs of the FCG. i.e. volunteer assistance, support groups.

This study found that the FCG initiated conversation about their own employment 29 times, and in 19 of these, the nurse did not pursue further questions/conversation about caregiver employment. The nurse initiated the conversation about the FCGs' employment 3 times and their own employment 14 times. There were 32 instances of conversation about employment of others, unrelated to the FCG or nurse.

The results found that FCGs initiate employment conversations more frequently than nurses, and nurses do not often engage in further conversation about FCG employment when it arises. This suggests there is a window of opportunity for hospice nurses to better support busy, often overwhelmed employed family caregivers. Further research is needed to examine employment conversations between nurses and FCGs to understand the impact on FCG's well-being.

INTRODUCTION

Families Caring for an Aging America defines a family caregiver as anyone who provides any type of care to a loved one who is ill or disabled and states that over 17.7 million Americans are providing help to 7.7 million Americans who are parents, grandparents, spouses, neighbors, and friends who have mental, physical, and cognitive needs (Schulz & Eden, 2016).

Within the past couple decades, the age expectancy has rapidly increased, resulting in a greater need for health care services for the older generation (Suzman et al., 2015). Living longer means individuals are living with chronic illnesses such as dementia, Alzheimer's, cancer, among other comorbidities. These create a stress on the health care system as well as create a need for increased support from family members to help with day-to-day activities (Schulz & Eden, 2016). This rise in life expectancy increases the need for more family caregivers (FCGs), but unfortunately the United States has a shortage of FCGs to compensate for the rise in demand (Schulz & Eden, 2016). One of the reasons America is not able to properly supply FCGs is because women, who are the majority of family caregivers, are entering into the workforce at higher rates than ever before (Schulz & Eden, 2016). When family caregivers are employed full-time, they are more likely to choose an alternate form of care for their loved one. In the past four decades, women's involvement in the workforce has grown by 19 percent: an increase from one in three women working, to one in two (Toossi, 2013). Some other factors influencing supply and demand of FCGs are smaller families due to lower fertility, higher divorce rates, more childless marriages, and a lack of marriage; older adults are geographically isolated from children; and step-children don't feel the same duty to take care of a step-parent (Schulz & Eden, 2016). It is expected that the gap between supply and demand will only continue to widen because of these factors.

Because the rising age expectancy has put a burden on the health care system, without family caregivers the healthcare system would be overloaded and not properly able to meet care recipient needs (Schulz & Eden, 2016). In the past, before the addition of Medicaid, Medicare, the Older Americans Act, and Social Security, it was expected that children were to take care of their older parents out of love and duty (Feinberg & Levine, 2015). Now, children do not feel the same duty and with the addition of new services and growing numbers of retirement and nursing homes, many family caregivers are choosing to play a more hands-off role in the caretaking of their family members (Redfoot et al., 2013).

Some long-term services and supports (LTSS) worth mentioning are assisted-living homes, adult day services centers, subsidized senior housing, continuing care retirement communities, home health agencies, and hospice care agencies (Henning-Smith & Shippee, 2015). In 2015 there were 4,600 adult day services centers with 286,300 users, 12,200 home health agencies with 4,455,700 users, 4,300 hospice agencies with 1,426,00 users, 15,600 nursing homes with 1,347,600 users, and 28,900 Residential care communities with 811,500 users in the United States (National Center for Health Statistics, 2019). For the sake of this research paper, the focus will be on hospice care.

Hospice is comfort care rather than curative care and is different from palliative care because palliative care is any type of care administered unto a patient with a life-

threatening illness or disability. Hospice care is comfort care which serves to aid patients who have a terminal diagnosis of six months or less (Torpe & Golub, 2015). Many families chose hospice care because it allows the patient to reside in the comfort of their own home. According to the National Hospice and Palliative Care Organization, most hospice care takes place inside the home but can also be administered in hospitals, nursing homes, hospice facilities, and other long-term care facilities (Hospice Care, 2019). Hospice care is covered by Medicare, Medicaid, and most other health plans and thus is a great resource to families facing financial burden (Torpe & Golub, 2015).

Many families choose hospice care services so that the patient can maintain their dignity, families can have a more hands-on role in the patient's final days, and patients can feel more comfortable in their homes.

Hospice care programs allow the family caregiver to play a crucial role in the healthcare needs of the hospice patient. Hospice caregivers can provide care for two reasons: to provide care to an individual because of health or functioning reasons, or to provide care to an individual with high needs, such as a patient with dementia or a patient who needs help with two or more self-care activities (Schulz & Eden, 2016). The caregiving needs associated with the latter type are more advanced and may continue to worsen with illnesses that advance over time such as dementia, Parkinson's disease, and cancer (Schulz & Eden, 2016). The duration of care can depend heavily on the illness and may sometimes require the FCG to provide care for more than twenty years (Schulz & Eden, 2016). A caregiver may provide care for multiple people at different times in their lives.

Types of Care Provided by Family Caregivers

There is large diversity in care provided by family caregivers. Some examples of responsibilities include household tasks, such as managing money or home maintenance; providing self-care needs such as bathing, feeding, and toileting; health and medical care such as operating medical equipment and providing wound care; advocacy and care coordination such as communication with health care personnel and insurance issues; and surrogacy such as property management and financial matters (Schulz & Eden, 2016). Many patients may only need help with household chores, whereas advanced patients, such as those with advanced cancer, will need advanced care. Hospice programs rely on FCGs to help with medical support, especially in the case of cancer, because the illness often consists of rapidly changing care recipient needs particularly related to pain management. Cancer FCGs may be responsible for operating machines, providing medications via patches, intravenously, by mouth, and by injections, providing care of catheters, feeding tubes, wound care, infusion pumps, acute condition management, and management of tracheostomies (Talley et al., 2012). All of these skills require proper training to ensure proper care. This is an additional stress placed on the FCG to run machines and administer medications in the appropriate manner. Complex medical care demands can be a risk factor for caregiver burden.

Caregiver Burden

The term 'caregiving burden' can be described as "a negative reaction, which is a multidimensional concept that stems from the imbalance between the social, psychological, and economic consequences permeating a care situation and the

caregivers' coping strategies to meet the demands of patient care" (Given et al., 2012, pg. 241). The level of caregiving burden is dependent on the number of care needs, comorbidities, and the amount of time a caregiver must devote to caregiving. It was found in a study that cancer caregivers and dementia caregivers had the highest level of caregiving burden (Kim and Schulz, 2008) meaning that cancer and dementia FCGs were more likely to experience negative psychological effects and more likely to put the patient at risk for neglect.

Prior research suggests that the average amount of time spent providing care to individuals with high needs was an average of four years; caring for individuals with two or more self-care needs the average was five years (Schulz & Eden, 2016). Helping someone with high needs means that the FCG must be in close range for many hours of day which can exacerbate the stress on the family caregiver.

The functionality of a patient determines the time a caregiver spends caregiving per month and is different for each family. On average FCGs spend roughly 85 hours per month providing care to individuals who needed only household cleaning help, while caregivers who provided care to an individual with three or more self-care needs spent roughly 253 hours per month. This is the equivalent of two full-time jobs (Freedman & Spillman, 2014.) On top of this it is estimated that half of all FCGs are employed (Schulz & Eden, 2016) therefore between working full-time and caring full-time, a FCG has very little time for their own personal needs and activities. This puts the FCG at an increased risk to develop negative psychological effects.

With the addition of new care responsibilities in a family caregiver's life it is easy for family caregivers to become overwhelmed and their well-being can suffer as a result. How well caregivers can effectively manage caregiver burden is dependent upon available resources, knowledge, support systems, as well as their own personal skills (Schulz & Eden, 2016). This includes being able to balance personal life, such as employment and other personal activities, with caregiving as well as having effective coping skills to manage the stresses from caregiving.

Often people don't give up their daily activities but rather add them onto caregiving responsibilities. On the other hand, some people may find that their only options are to enter early retirement or give up other opportunities to allow them to make caregiving their highest priority. Giving up personal activities can consequently lead to a higher rate of caregiver burden and decreased quality of life (Schulz & Eden, 2016).

Although positive effects can occur from caregiving, caregiver fatigue can put individuals at risk for many adverse effects including their health, quality of life, relationships, and economic security (Schulz & Eden, 2016). Data from the NSOC shows that over 20 percent of caregivers find caregiving financially and physically difficult, while 44 percent report emotional difficulties (Schulz & Eden, 2016). The occurrence of negative effects is individualistic depending on the FCGs ability to handle the situation and the FCGs coping strategies.

Effects of Caregiving on Mental Health

Many caregivers reported having mental health issues including anxiety, depression and a decreased quality of life. Twenty-five percent of cancer caregivers (Kim et al., 2014) reported depressive symptoms after two years, compared to 14 percent of stroke caregivers (Haley et. Al, 2009) and an overall 22.3 percent in all caregivers

(Cuijpers, 2005). Hirst (2005) found that these symptoms were primarily seen at the beginning and end caregiving, although symptoms may also increase over long periods of caregiving. The American Cancer Society National Quality of Life Survey for Caregivers found that cancer caregivers that had cared for five years had higher rates of depression and anxiety and overall lower quality of life than non-cancer caregivers (Kim et al., 2014).

Effects of Caregiving on Physical Health

Caregivers may also experience physical health effects. It was found that by analyzing various studies, high-stress caregiving caused increased mortality, self-reported health concerns, more negative hormonal effects, impaired health due to sleep, diet, and smoking problems. (Schulz & Eden, 2016). In a study done by Ji and Colleagues they found that the rate of coronary heart disease and stroke was much higher in spousal cancer caregivers (Ji et al., 2012). The highest problems in cancer caregivers in another study were sleep disturbance, pain, fatigue, weight loss, and loss of strength and appetite (Stenburg et al., 2010). Aside from these health effects, caregivers may also experience caregiving-related injuries such as back injuries from carrying heavy objects (Schulz & Eden, 2016). Additionally, caregiving is associated with health risk behaviors such as smoking, alcohol abuse, substance abuse, not enough sleep, poor diets, and a lack of physical activity that could cause further health problems (Schulz & Eden, 2016).

Effects of Caregiving on Social Health

A caregiver's social health can be impacted in a range of different ways from effecting family relationships to social activities. This could mean a loss of social support. The most extreme examples of this are divorce and spousal abuse (Schulz & Eden, 2016). These social effects can in turn result in further mental effects such as depression and *decreased* quality of life.

Effects of Caregiving on Financial Health

Caregiving places additional burdens on a family caregivers financial health. In a recent study it was found that caregiving increases poverty among women in later life (Reinhard & Feinberg, 2015). This financial burden can be due to caregiving expenses as well as the need to stop working to provide additional time for caregiving. Additionally, caregiving jeopardizes job security and consequently retirement, social security, and financial well-being (Schulz & Eden, 2016). The 2015 Retirement Confidence Survey found that 19 percent of retirees left earlier than expected to fulfill a family caregiving role (Helman et al., 2015). Other surveys suggest that 61 percent of employed caregivers leave work early or late, take more time off for care management, and reduce responsibility (Qualls, 2009). These effects can reduce income substantially.

Consequences of Caregiver Fatigue on Caregiving

Caregiver fatigue can affect not only the caregiver, as previously mentioned, but can also negatively affect the individual needing care in many different facets. One of the most potent effects of caregiver fatigue is elder mistreatment and neglect (Schulz & Eden, 2016). Elder Mistreatment is sexual abuse, abandonment, or financial exploitation; Elder neglect is the intentional act of physically, emotionally, or socially harming an elder (Schulz & Eden, 2016). Some ways to prevent the harmful effects of caregiver

fatigue are through support and programs provided to the family caregiver. Communication between the hospice nurse to assess the needs to the caregiver can be beneficial to reduce the negative impacts of caregiving on care provided (Ellington et al., 2011).

Services Available to Family Caregivers

Programs and Supports for Family Caregivers can make the difference in preventing neglect and mistreatment of older adult and providing the best care. In order for family caregivers to carry out their responsibilities and not be negatively affected they must have proper education, support, and training (Schulz & Eden, 2016). For a broad category of caregivers there are many caregiver interventions at many different levels, one of which includes family meetings that support the family caregiver and can include education, behavioral therapy, stress management, and skill building (Schulz & Eden, 2016). Because cancer caregivers face special concerns, there are specific intervention strategies for cancer caregivers which can improve quality of life for the caregiver along with self-sufficiency (Schulz & Eden, 2016). Additionally, there are special programs, respite care, that provide temporary care for the patient to allow the FCG to have relief from caregiving for several days. Hospice programs also offer aide assistance to provide the patient assistance with activities of daily living.

Supportive Needs of Caregivers

Although some caregiver intervention programs prove effective, more research is needed, as well as often the family caregivers are unaware of the resources available. There is little known about employed hospice family caregiver needs and if the hospice team supports those needs. In hospice care programs, a multidisciplinary team is used to ensure the comfort of the patient, but the family caregiver is an integral part of success. The health and needs of the family caregivers should be assessed and resolved by the visiting hospice nurse and aides because of their opportunities to interact with the family and hospice patient. It is their responsibility to make sure the family caregiver is educated and trained on their own responsibilities including medication administration and machine operation. To ensure the success of the family caregiver, the visiting hospice nurse should assess the caregivers needs which include employment related issues and other responsibilities and should be able to suggest support systems and other programs which can benefit the health of the family caregiver.

The purpose of this study is to determine if visiting hospice nurses are assessing the needs of family caregivers specifically to determine whether the family caregiver expresses increased stress due to employment. The study is done with cancer hospice patients, which have increased needs and therefore, as previous research has shown, increased caregiver burden. It is also important to ascertain whether or not the hospice nurse suggests resources available to the employed family caregiver to potentially help prevent caregiver fatigue, negative effects on caregiving, and decreased quality of life.

METHODS

Parent Study

This present study was conducted using data from a large parent study (P01CA138317PI) consisting of a multi-site prospective observational longitudinal study,

which examined audio recordings from in-home hospice nurse visits with advanced cancer patients as well as their spousal family caregivers. From the parent study, a secondary data analysis was conducted of hospice nurse visits to 70 cancer patients and their families. Inclusion criteria for caregiver eligibility are shown in Table 1 below. When multiple nurse visits were recorded for a patient and family, one was randomly selected for inclusion in the analysis. If a visit did not include caregiver speech, a different visit of the same patient was randomly selected. All of the procedures used in this study were approved by the home hospice agencies and the University of Utah Institutional Review Board.

Inclusion Factors
Patient had cancer
Patient-caregiver dyad spoke English
Caregiver was cognitively able to participate
Dyad was 45 years or older
Spouse/Partner is the primary caregiver
Visit occurred in the patient-caregiver home

Table 1. Inclusion Factors for the Parent Study

The sample for the parent study recruited nurses from participating hospice agencies from the Intermountain West (8) and the Northeast (2) and caregiver and patients were recruited based on participating nurse caseloads. Data collection was carried out between August 2011 and December 2014.

Procedures for Parent Study

Nurses participating in the study were given and trained to use digital recorders and were asked to record all of their in-home hospice visits with participating patient-caregiver dyads. Further each nurse was asked to begin the recording by saying their own name, the patient’s name, and the date. The nurses were also instructed to inform the patient and FCG that they were recording and that the cessation of the recording could happen at any time upon patient-FCG request.

Digital audio recordings of visits were uploaded to a secure server by study staff. Recordings were then transcribed and the nurse, patient, family caregiver, and any other speaker were identified in the text each time they spoke. Identifying information was taken out of the transcripts to ensure privacy.

Present study

For the present study, transcribed visits which were chosen based on key words related to employment. It was found that 34 of the 70 transcripts met the criteria for employment-related terms. A text-word search was then done for mention of employment descriptor words which were employment, job, employee, work, supervisor, boss,

manager, and employer. These transcripts were then coded for the type of nurse-FCG interactions by the code book in Table 2 related to employment.

Nurse-Family Caregiver Interactions Related to Employment	
FCG initiates conversation about own employment	Nurse asks further questions
	Nurse does not ask further questions
Nurse initiates conversation about FCGs employment	
Nurse initiates conversation about own employment	
Conversation is had about employment of a third-party	
Nurse mentions volunteers	
Nurse mentions *FMLA	
Nurse offers resources	

Table 2. Categories for Nurse-Family Caregiver Interactions Related to Employment
*FMLA-Family Medical Leave Act

These categories were developed inductively throughout the coding process. Additional subcategories were included for the main category: FCG initiates conversation about own employment to assess whether the nurse asked follow-up questions about the FCGs work or offered supports provided by the hospice agency such as hospice program volunteers and respite care.

A code was assigned for each conversation about employment instead of number of times mentioned. This was done to avoid getting multiple instances resulting from one conversation or speech. This information was then double-coded by two different coders to ensure accuracy and avoid coder-drift. The results from the two coders were then cross-referenced and adjustments were made to provide unity between the two results.

RESULTS

Demographics

The study demographics are outlined in Table 3. Because spousal caregiving was an inclusion factor in the parent study it was determined that the relationship to patient was spouse. There were 65 instances in which the patient and family caregiver was married and 5 instances where the dyad was not legally married but were in a common-law marriage. For the instances in which the patient and primary caregiver were married the average length of marriage was 35.9 years and the average age of the caregivers in the sample study at the time of data collection was 64.9, with the majority of caregivers being female (62.9%) and younger than the patients.

It was also determined that 28 (40%) FCGs were employed at the time that the study occurred. 8 of the family caregivers were employed part-time while 20 were full-time employees as displayed in Figure 1.

Caregiver Characteristics	N(%)
Relationship to Patient Spouse	70(100)
Gender Female Male	44(62.9) 26(37.1)
Marital Status Married Other	65(92.9) 5(7.1)
Race White Black Missing	68(97.1) 1(1.4) 1(1.4)
Hispanic/Latino Descent Yes No	5(7.1) 65(92.9)
Education Level High school Some College College Some Graduate School Graduate School	16(22.9) 26(37.1) 15(21.4) 4(5.7) 9(12.9)
Annual Income Less than 10,000 10,000-24,999 25,000-39,999 40,000-49,999 50,000-74,999 75,000 or more Prefer not to answer	2(2.9) 11(15.7) 7(10) 9(12.9) 21(30) 14(20) 5(7.1)
Adequacy of Financial Situation Not very good Comfortable More than adequate Missing	13(18.6) 42(60) 14(20) 1(1.4)
Employment Not Employed Part-time Full-time	42(60) 8(11.4) 20(28.6)
	M(SD)
Age at Last Birthday	64.9(11.4)
Number of Years in Present Relationship (N=65)	35.9(17.6)

Table3.Demographics for Caregivers Collected for Parent Study

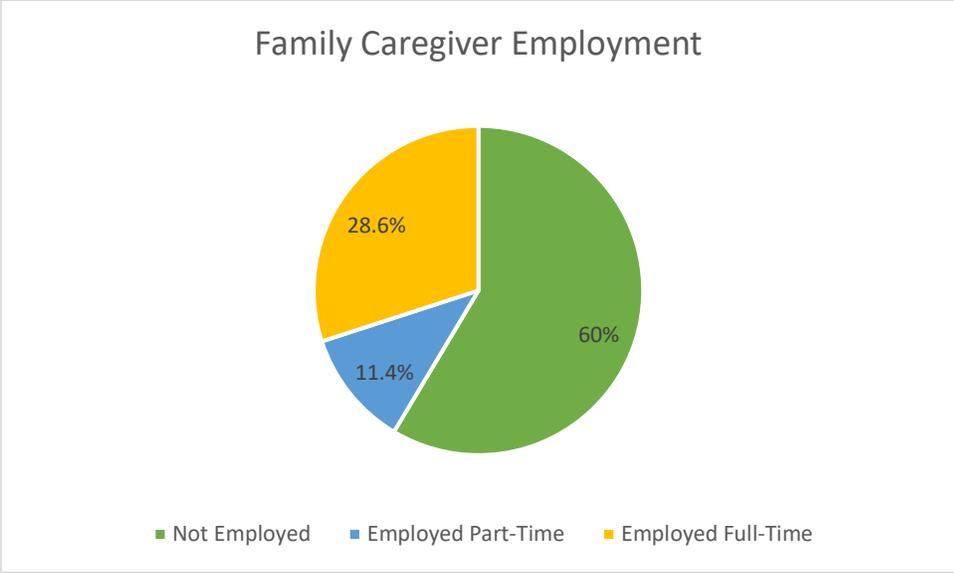


Figure 1. Types of Family Caregiver Employment Percentages

Findings

Thirty-four transcripts were chosen from the total sample of 70 from the parent study because they had one or more mention of work-related speech. A secondary analysis discovered that in the 34 transcripts there were a total of 78 mentions of employment as shown in Table 4, which translates to an average of 2.3 mentions of employment per transcript. This was further categorized and it was found that the FCG initiated conversation about their own employment 29 times, the nurse initiated the conversation about the FCG's employment 3 times, the nurse initiated conversation about their own employment 14 times, and there were 32 instances of conversation about employment of others, not FCG or nurse-related. This equates to 9.38% of employment conversations about the FCG mentioned by the nurse and 90.63% mentioned by the FCG.

FCG Initiates Conversation About Employment	29
Nurse Asks Further Questions	5
Nurse offers suggestions/advice	5
Nurse Does Not Ask Further Questions	19
Nurse Initiates Conversation About FCG Employment	3
Nurse/FCG Initiates Conversation About the Employment of Others	32
Nurse Initiates Conversation About Own Employment	14
Nurse Offers Resources	6
Nurse Mentions Aide	3
Nurse Mentions Volunteers	2
Nurse Mentions FMLA	1
All Interviews	70
Interviews Pulled	34
Total Times Employment Conversations Occur	78
Average Number of Times Mentioned per Transcript	2.3
Percent FCG Employment Mentioned by Nurse	9.38%
Percent FCG Employment Mentioned by FCG	90.63%

Table 4. Summary of Findings from Mention of Employment

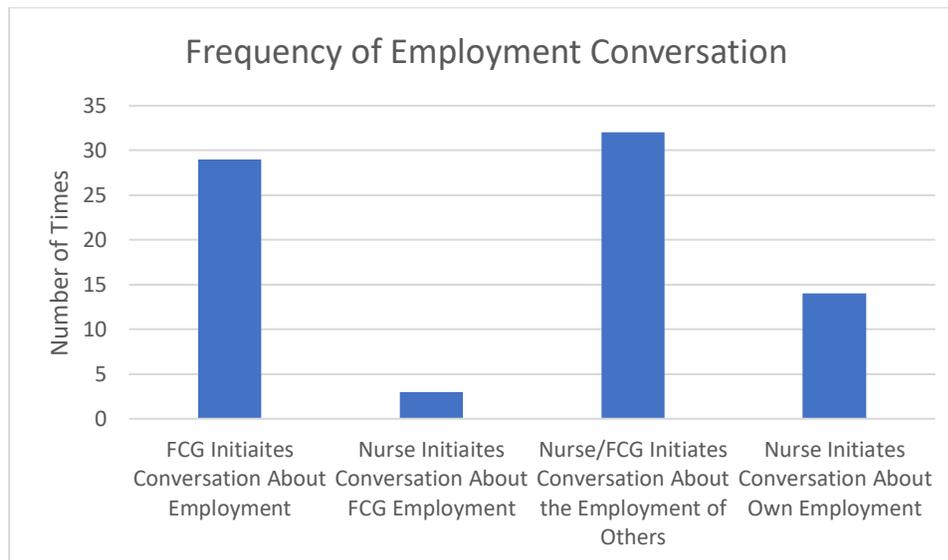


Figure 2. Comparison of Frequency of Types of Employment Conversation

The category of FCG initiation was then further examined and found that of the 29 times the FCG initiated conversation about their own employment, 5 times the nurse

asked further questions. The other 19 instances the nurse did not respond directly to the conversation about employment. Five times the nurse offered advice such as “a new job isn’t a good idea” and advised the FCG to sleep and journal to curb stresses related to work and caregiving.

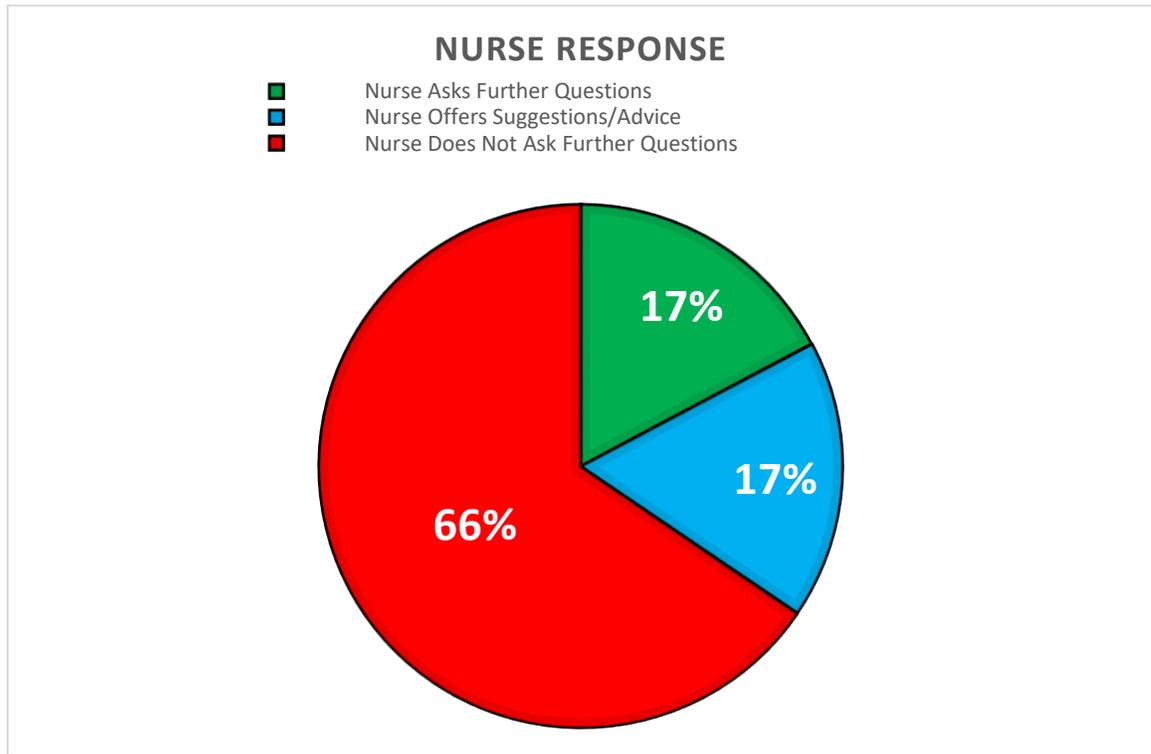


Figure 3. Summary of Nurse Response to conversation about FCG employment

The times that nurse offered resources they mentioned and explained FMLA once, offered an aide 3 times, and a volunteer once. Some of the strategies used by the nurse to ask the FCG about employment and stresses was to ask if they were feeling overwhelmed and/or able to handle the stresses of work with the stresses of caregiving.

DISCUSSION

The results of this secondary analysis offered insight into the communication between hospice nurses, patients, and family caregivers related to employment. After analyzing the data, it was determined that nurses do not engage in abundant communication about the family caregiver’s employment status and resulting stress level and emotional well-being.

The study found that the majority of conversations about the family caregivers’ employment was initiated by the family caregiver and the nurse did not carry on the conversation by asking questions or offering support. There were only 3 times in which the nurse initiated the conversation.

In *Patient Safety and Quality: An Evidence Based Practice for Nurses* the authors note that sometimes the family caregiver is referred to as the ‘secondary patient’ that is

because they are also in need of guidance and support (Hughes, 2008). As previously mentioned, the family caregiver is at a high risk for injuries and other adverse health effects. If the FCG experiences significant caregiver burden, this puts the patient at risk for decreased care and therefore health consequences. Because of this it may be important for the nurse to think of the FCG as a 'secondary patient'.

Family caregivers provide for their family members and must be instructed how to do this properly. Aside from physically taking care of the patient, it is also important for the family caregiver to know how to take care of the patient and themselves emotionally. This is especially important because the end of life can be very emotionally taxing for all parties involved.

There is limited research on intervention strategies used to alleviate caregiver stress and risks. Hughes suggests that an intervention strategy which first, puts the family caregiver as a client, emphasizing both their health and support needs. Secondly the intervention should focus on instilling confidence and self-efficacy without the caregiver. This leads to increased quality of care and decreased caregiver distress (Hughes, 2008).

In order to help increase this confidence it is important to assess the caregiver for potential risks to the quality of care. One of these potential risks is the family caregiver's employment. Providing care at the end of life can be very stressful to the FCG and they may feel that they do not have enough time to provide adequate care balancing employment and caregiving. In a study done by Sylvia Orodnenker results found that of employed family caregivers the most common reported burdens were employment distributions (having to switch hours at work or change number of hours) and financial burdens caused by an FCG's inability to work. These stresses can often be diminished by the use of a hospice aide and respite care, among other strategies.

Because the nurse is often the member of the health team the patient and family caregiver are most in contact with, it is beneficial for the nurse to initiate conversation about employment with the FCG. A study found that often caregiver burden is most associated with a lack of self-efficacy and inadequate preparation to perform required skills. This same study also concluded that interventions targeted to family caregivers benefitted both the family caregiver and the patient and that caregivers who received the intervention experienced less burden, lower rates of depression, and greater mental and physical health (Northouse et. Al, 2012).

In the case of the present study, often the FCG is the first to mention employment, in which case the nurse could possibly follow up with questions such as "how do you feel like working full-time is impacting your care of the patient" or "do you feel like you would benefit from an aide or a volunteer". It may be helpful to the family caregiver if the nurse acknowledges and empathizes the level of responsibility and stress the family member may feel while also supporting these caregivers in accessing additional support. Lastly it would be beneficial for the nurse to know what resources their agency offered to the patient and family caregivers and offer those to the dyad. This may be an area that benefit from further research into caregiver employment and intervention strategies.

Limitations

While 34 transcripts were included in the secondary analysis, there were only 28 family caregivers which were employed. We chose to review all 70 transcripts, even

though some caregivers were retired or could be unemployed because of caregiving, because we wanted to capture all potential conversation about employment.

Because only one transcript per nurse-patient-family caregiver triad was chosen, the chosen transcript may not be an accurate display of typical employment conversation between the nurse and the FCG. The nurse could have asked the family caregiver about work during previous visits.

Conclusion

The results of this study offered insight into the communication about employment between hospice nurses and family caregivers. FCGs initiate employment conversations more frequently than nurses, and nurses do not often pursue further conversation about FCG employment when it arises. Further research is needed to examine frequency, context, and content of conversations about employment between FCGs and nurses to understand how this may impact FCG well-being.

ACKNOWLEDGMENTS

A special thank you to Dr. Megan Hebdon, Sara Bybee, Shirin Hiatt, and Dr. Lee Ellington in the College of Nursing at the University of Utah who made this project possible through guidance and support. This project would not be possible without the parent study and the many family caregivers, patients, and hospice nurses who participated.

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